A Rhetorical Perspective on Trust in E-Health Websites

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Abstract

This dissertation is centered on the issue of trust in e-health, a product of the internet opening access to information at a broad scale. Medicine, as a discipline whose authority has traditionally been based upon expertise and hierarchy between physician and patient, is one domain in which this increased access has led to special concern. My study intervenes in ongoing discussions about e-health information by asking "How does trust operate in e-health sites?" and does so from a rhetorical perspective. Through a comparative rhetorical analysis of three e-health sites that represent a continuum of informational to interactive, I found that trust operates in e-health sites in ways one might expect such as the use of credibility features to construct an expert ethos, but trust also operates socially in newer ways that are based upon community and personal experience, aligning with the broad shift to Web 2.0. This study has implications for the field of rhetoric and technical communication, in that it poses trust as a viable framework for understanding online information rhetorically and views e-patients as citizen technical communicators. This study also has implications for the design of trustworthy e-health communication.

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Chapter 1: Introduction

When I was growing up, if someone in my family had a medical question, we would break out our copy of the *Family Medical Guide* (1982), a hard-cover, navy blue tome with the symbol of the American Medical Association on the front. The book was essentially an encyclopedia, its interactivity limited to a section of flowcharts near the back. By answering a series of yes/no questions, I could follow the arrows until I was reassured that I was experiencing, say, heartburn, rather than something that required a visit to the doctor. While the fact that my family had such a book is already interesting in that, for hundreds of years, most people got their medical information exclusively from a doctor, the amount of medical information that I can now access on the internet is seemingly infinitely more, and my approach to medical research for myself and my family has changed accordingly. I have checked off symptoms using WebMD's Symptom Checker tool in order to narrow down to a possible diagnosis. I have searched for peer-reviewed medical studies. I have consulted blog posts and discussion forums in which lay people share their opinions and experiences regarding health issues.

I am not alone in my use of the internet to research health topics. Since the internet grew from its roots as a resource for academics and computer-savvy individuals to being a fixture in many homes in the 1990s, the approach to patient[1] health research has been shifting. For many years now, "Googling" symptoms and

[1] I acknowledge that "patient" can be a limiting term for describing people who use the internet for health purposes, as it defines them in terms of their relationship to the medical establishment. Regardless, for the purposes of this study, I consider "patient" (or "e-patient') to be a straightforward way to describe who is going online for health information.

conditions has been a typical patient practice,[2] but some medical professionals are still pondering what to do about the patient who, referencing internet printouts as evidence, is convinced of a questionable self-diagnosis. Web 2.0, or the participatory web, has shifted things further; it has enabled new levels of interactivity not just with medical information but with other patients. In this new context of the patient-participatory web,[3] it is not uncommon for today's patients to discuss health questions in a social media site in lieu of a call to the doctor or to share their stories on a blog for friends and strangers alike to read.

The internet has opened access to content traditionally reserved for medical experts, and it has allowed patients the opportunity to contribute to and comment on this content. In contexts like medical social networks, patients act as "citizen technical communicators" – accessing, interpreting, and communicating about complex technical and medical topics – in ways they never have before, influencing the doctor-patient relationship, patient agency, patient health, and views of authority.

Health and medicine is just one realm which has seen this "democratizing" effect of the internet. Crowdsourced or citizen science, the participation of lay people in scientific research, has taken off in popularity. The internet has enabled citizen participation in politics at unprecedented levels, as demonstrated by the Arab Spring protests in 2010. Citizen journalists have broken news stories faster than professional

[2] According to a Pew study, as of 2012, 72% of U.S. internet users had gone online for health information in the past year (Fox & Duggan, 2013).

[3] Other scholars have called this overlap between Web 2.0 and medicine "Med 2.0" or "Health 2.0." My term for this overlap is "patient-participatory web," which I prefer because it places emphasis on patients and their involvement, rather than on the technology or medicine as an institution. See Chapter 2, Literature Review, for more on Web 2.0 and e-health.

journalists. Smartphones and mobile apps have further facilitated internet users' near constant access to information and others.

Despite claims in the popular press of the power of the internet and specifically the social web to change world history, flatten traditional hierarchies, or cure diseases, this shift is not without problems. "Too much information" is a double-edged sword. In the introduction to their edited collection on ethos and credibility in digital environments, Folk and Apostel (2012) say of this conundrum:

> [T]he constantly evolving nature of digital information and the digitally-infused societies producing and assessing that information means that no fixed solution will be a panacea. However, this problem of trusting information is not simply an element of ubiquitous technology so much as it is an ongoing aspect of human nature, one that has been evident since the origins of debate and open societies. (p. xvii)

In other words, navigating the questions of who and how to trust is nothing new – it is inherent to being human. Technology, however, has complicated matters, and will continue to do so as it evolves.

A Rhetorical Perspective on Trust in E-Health Websites

In regard to medicine, current issues like the anti-vaccination movement or global health crises like Ebola have renewed concern about issues of online trust of medical information. There is a lot of good, helpful, potentially empowering medical information out there on the web. But there is also unproven information, accurate but irrelevant information, accurate but biased information, well-intentioned misinformation, and outright scams. Without the traditional gatekeeping mechanisms of peer review or physician guidance, e-patients are left with the difficult decision of which information,

and which people, to trust. In the context of e-health[4] on the web, where the lines of rhetor/audience, expert/nonexpert, and public/private are blurred, how does trust operate?

This purpose of this dissertation is to address this broad question through a rhetorical analysis of e-health sites. My study consists of comparative rhetorical analyses of three types of e-health websites: a governmental e-health site, a commercial e-health site, and a patient social networking site. The selection of sites represents a continuum from informational to interactive, allowing me to observe the range of rhetorical means used to establish trust in traditional, top-down e-health sites versus patient-based, bottom-up ones. Patient communities are a particularly interesting and novel context in which people are consulting and contributing to technical, medical information on the web. Therefore, I followed up my website analyses with a closer look at an online medical support group and how trust operates in that context.

I am approaching this study as a rhetorician. The way that rhetoricians typically "get at" the larger issue of trust is through the theoretical concept of ethos – Aristotle's term for a speaker's credibility leveraged for persuasion. Trust is established, in part, by rhetorical means such as a credible ethos, so when we talk about credibility and ethos, we are really talking about a rhetor's attempts to create trust. However, it is important to acknowledge broader dynamics at play when it comes to trust than just the rhetor's projection of a trustworthy and credible character. Therefore, I bring the larger frame of trust to my study. Trust has been studied in many other disciplines (computer science,

[4] I use the term "e-health" to refer to the overlap of the internet with health and medicine. See Chapter 2, Literature Review, for a more detailed discussion of the term.

psychology, sociology, etc.), with recent focus on online trust. This work, when added into the rhetorical toolkit, can provide a broader perspective on the ways that trust is established in e-health sites and in patient communities. According to Whitty and Joinson (2008), "Trust is of utmost importance if relationships and communication are to exist online" (p. 5). Others have described trust online as a "leap of faith":

> We type in our credit card numbers and other personal information in order to make purchases over the Internet and trust that this information will not be used in unauthorized or fraudulent ways. We write frank and confidential messages to our close colleagues and friends and trust that they won't circulate these messages to others. We trust anonymous fellow chat room and newsgroup members with our private thoughts and dreams, and because of the intimacy such self-disclosure creates, come to trust them enough to give them our phone numbers. (Bargh & McKenna, 2004, p. 585)

I would add online health research to the list of online activities that require trust. Making medical decisions on the basis of an informational webpage, acting on advice shared in a patient forum, or disclosing personal health information online: All of these actions place users in a position of vulnerability.[5] Yet the growing importance and scope of e-health as a resource for today's patients suggests that people are finding ways to navigate the problem of trust online, even in the newest participatory spaces.

Background on E-health Websites

Patients have vast options in terms of e-health sites. Standard informational health sites abound, including commercial websites like WebMD (the most popular

[5] I wish to emphasize that many people use e-health to actually make medical decisions – to decide whether to seek medical attention or treat a condition themselves. Fox and Duggan (2013) call these people "online diagnosers," and the researchers found that 35% of people surveyed had gone online specifically for this purpose. This statistic underscores the importance of *trust* as a frame for examining e-health. People are not just reading e-health articles for fun or for general edification – they *act* on it. In many cases, people are dealing with real, physical concerns. In such cases, people require more than just a sense of the character and credibility of a webpage; though these things are important, patients ultimately need to be able to *trust* information enough to make a decision.

health website), MedicineNet.com, or Yahoo Health; governmental sites such as NIH.gov, healthfinder.gov, or CDC.gov; and sites published by medical institutions such as the Mayo Clinic or Cleveland Clinic. Patients can also find many specialized sites focusing on aspects such as pediatric health, alternative medicine, or specific conditions.

Patient participation is the future of e-health, whether in the context of health-focused social media sites or even the incorporation of interactive aspects into traditional information-based sites. Although the social web offers many options for patients, they are newer and less familiar than some of the e-health sites listed above. Many patients use standard social networking sites like Facebook or Twitter to post and exchange medical information or form groups for support, but several health-focused sites have cropped up to meet these needs in more specific ways (Newman, Lauterbach, Munson, Resnick, & Morris, 2011).

Some of these sites could be considered patient or medical social network sites in that they are designed to connect individuals,[6] though some bill themselves as health information sharing sites, perhaps to capture the broader purpose of collecting and crowdsourcing patient health data in addition to offering support communities. To provide just a sample of the new patient-participatory sites available, DailyStrength.org and Inspire.com consist largely of support communities for various conditions. SmartPatients.com combines communities with a clinical trial search. MedHelp.org provides communities, self-tracking tools, and articles. EverydayHealth.com offers

[6] A classic definition of social network sites, from boyd and Ellison (2007), is "web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system" (para. 4).

condition-specific blogs and health tracking apps, as well as expert content. WebMD, though best known as an informational site, has added patient communities. Some sites focus on crowdsourcing medical data and user evaluations of treatments, such as CrowdMed.com, CureTogether.com, and PatientsLikeMe.com; other information sharing sites are condition-specific, such as Crohnology.com. 23andMe.com is an online direct-to-consumer genetic testing company. Although it now focuses on ancestry, it had been providing genetic health information to consumers prior to the FDA banning it in 2013.[7] Treato.com collects and indexes patient-generated content from all over the web. Some sites, like HealthGrades.com, are places for patients to review physicians and hospitals; others such as Askapatient.com are specific to medication reviews. All in all, there are many outlets for the patient voice online.[8]

While I will review scholarly literature about e-health in Chapter 2, for now I offer an informal survey of what the popular press has been saying about e-health. These media accounts reflect and shape public thinking and help to capture the simultaneous enthusiasm and concern surrounding the topic. In terms of popular press coverage, it seems that the topics of e-health and medical social networking peaked around the early 2010s; this is around the time that several prominent news outlets such as *The Guardian, The New York Times*, and *Time* picked up on the trend and began exploring its promises and pitfalls.

[7] This event gets at the heart of concern about patient access to data traditionally only available to professionals.

[8] There are many other sites that facilitate communication between patients and their physicians (patient portals) or physician-to-physician networking, but such sites are beyond the scope of my research on patient-based e-health sites.

In terms of positive aspects of e-health, many have acknowledged patients' need for social support. Online support is not new, but as medical social networks become mainstream, patients have more opportunities to connect with others. Social networks are especially helpful for connecting those with rare diseases (Meyer, 2012) or who are homebound or disabled, and who may therefore lack an in-person support network (Miller, 2010). Some websites, like CaringBridge, are set up to allow patients and caregivers a way to broadcast news and updates and receive support from family and friends (Higgins, 2014).

Patients can receive advice and information about their condition even in support-oriented sites. But with the surge of interest in medical crowdsourcing, patients may also learn from data generated from their own and others' self-tracking of symptoms and treatments. This type of information can fill a need for patients, who may have received only cursory information about a prescription from a physician (Bleicher, 2008). Patients can even crowdsource mysterious conditions, submitting their case to a team of "medical detectives" on a site like CrowdMed to narrow down to possible diagnoses (Gustke, 2015).

Some media reports have also praised the possibility for patient-generated data to influence more than just individual patients' experience, but medical science as a whole. According to Higgins (2014), "With a motivated force of passionate and unpaid foot soldiers providing and annotating data, information about diseases and – something that isn't always well documented in research – rich data about patient experience – the potential for improved treatments is alluring" (Higgins, 2014, para. 10). Singer (2010) noted that patient-entered information can serve "as an early warning signal" for drug side effects, whereas it typically takes years for serious side effects to

emerge, and for drug companies to notice. She also points to two cases in which patient-generated data revealed insights unbeknownst to medicine. Data from CureTogether showed evidence of a link between vertigo, pain, and a migraine medication, paving the way for more scientific studies of this link. On PatientsLikeMe, a group of ALS patients banded together to conduct a small-scale, informal trial to see if lithium had any effect on symptoms, and they found the answer before official clinical trials did. These stories have led to much excitement about the ability of these websites to speed up the research process and lead to medical breakthroughs. Findings generated by some of these sites have been published in medical journals, showing that they are being taken seriously (Sharp, 2012).

Another major benefit of e-health sites is the role they play in empowering patients. Al-Ubaydli (2012), a medical doctor, comments on how patient participation online can create a more informed patient and therefore a more egalitarian, collaborative doctor-patient relationship. Doctors can even learn from patients' online research. According to Meisel (2011), also a medical doctor, a patient's "Google stack," as he calls it, can actually help medical providers diagnose more quickly. Al-Ubaydli suggests that doctors learn from e-health sites about how to communicate specialized information. He says, of personalized reports that patients bring in from sites like 23andMe, "They teach statistics and genetics far better than any medical school can and they teach us how to clearly explain complex genetic conditions to a patient" (para. 7). Higgins (2014) writes of this empowerment as a "new paradigm" in which patients no longer feel "at the mercy of a ruthless disease process but also of a system that seems at times to see them as guinea pigs for drugs and treatments, or as hostages to the limits of local practitioners" (para. 10).

The news articles that I read took a balanced approach to e-health, outlining potential dangers in addition to benefits. Unsurprisingly, many have expressed worry about the consequences of sharing traditionally private information in very open spaces. Discrimination in employment, housing, and health and life insurance is a well-acknowledged risk of medical data disclosure (Arnst, 2008). Higgins (2014) raises a caution about industry partnerships as a potential threat to privacy. Commenting on a 2014 partnership between PatientsLikeMe and Genentech that offers Genentech sweeping access to data, she noted that desperate patients and family members might be taken in by success stories and overlook a company's use of their data.

Patient data is extremely valuable. Even when companies do not intend to share patient data with companies, security may be compromised, especially given the growth in mobile apps for self-tracking. According to Dembosky (2011), "Imagining three years worth of heart rate data or depression symptoms travelling through mobile devices – potentially being offered for sale to drug or insurance companies, exploited by advertisers or hacked by cyber criminals – puts watchdog groups on alert" (para. 28). In fact, in 2010, Nielsen Buzzmetrics was found scraping personal data from PatientsLikeMe at a large scale, prompting some users to leave the site. Edwards (2010) said of this event, "don't kid yourself that PatientsLikeMe is the victim here: Its entire business model is about selling private patient information to the highest bidder" (para. 1).

This event raises another major concern about new data-based patient sites: accountability for companies who profit off of patient data. In the case of PatientsLikeMe, the company makes money by selling de-identified patient data to pharmaceutical and medical device companies. According to Singer (2010), users

"typically have no way of knowing whether their health profiles contribute directly to the development of more effective treatments — or are simply mined to create more effective drug marketing" (para. 11). What makes ambiguous data use particularly alarming, according to Edwards (2010), is the fact that there are computer programs and companies that can easily "reverse-engineer" anonymous data to identify the individual. In the case of sites that rely on advertising, people have expressed concern that drug and medical device marketing will overtake the sites (Aldhous, 2008), and consumers might not understand when they are being marketed to (Singer, 2010).

Misinformation has also been a major theme in popular press articles about e-health, paralleling broader concerns about the presence of bad information on the internet, given the lack of gatekeeping. Rheingold (2012) says, "along with the latest word on cutting-edge drug trials are unsubstantiated claims, rumors, and outright quackery" (para. 4). Some fear that patients, following online advice, could harm themselves (Chiang, 2014). If not physical harm, patients may still experience "cyberchondria" or increased anxiety from reading medical information. Some worry that negativity in a patient community could rub off on a patient (Miller, 2010).

Others wonder about what happens when online advice contradicts clinical advice. Gustke (2015) quotes a digital media professor who asks "What happens if you get a wrong diagnosis? Would you trust the crowd or go right to a specialist?" (para. 17). Similarly, Goetz (2008) asks "What's to keep patients from misinterpreting the streams of data and finding false hope — and what's stopping them from embarking on unproven and even risky treatments or dosages? And what happens if the real-world information at PatientsLikeMe contradicts the clinically proved protocols of medical science?" (para. 10). In data sharing sites in particular, there are acknowledged biases

that lead some to be skeptical of the usefulness of self-reported data. People who share medical data online are not representative of the full population (Neporent, 2012).

The above survey of the advantages and disadvantages of e-health displays the importance of trust in e-health. Patients can benefit from support, information, advice, and a greater sense of involvement in their healthcare. But in order to receive these benefits, they must take a "leap of faith" that their data will not be misused, that the website will not exploit them for commercial gain, that the information they read is accurate, and that peers are who they say they are. This challenge sets the stage for a study of how trust operates rhetorically in e-health sites.

Forecast of Dissertation

In this chapter, I have introduced the larger problem of trust in online health sites and how this dissertation will approach it rhetorically. I also provided an overview of e-health sites, including informational and interactive ones, and how the media has defined them in terms of benefits (support, information, medical advances, agency) and concerns (privacy, security, exploitation, misinformation).

Chapter 2, the Literature Review, provides scholarly background on e-health to set the context for my study, including aspects such as online peer support and patient ownership of data, and how e-health has aligned with the participatory medicine movement. In order to inform my analytical approach, I also review trust, and how other fields have addressed it through concepts such as ethos and credibility. I comment on how these issues have become especially complex as internet users have greater access to information and the ability to contribute information. Finally, I address work that brings together the topics of e-health and trust to clarify why further study is needed.

In Chapter 3, Methods, I describe my methods for conducting this study. I lay out my considerations for selecting websites, informational webpages, and a medical condition. I describe the method of rhetorical analysis and my specific analysis procedures. In addition, I explore the ethical complexities of research online and the limitations of the study.

Chapter 4 addresses how three different e-health sites attempt to establish trust in their organizations. I compare how rhetorical features in the pages that make up a user's first impression (such as the organizations' homepages and About pages) work to convey a credible ethos. The differences in the rhetorical strategies in informational to interactive sites suggest some of the new, personal ways that credibility is being conveyed on the social web.

Chapter 5 continues the comparative analysis of e-health sites and their attempts to establish trust, but looks to medical information pages within each site. It finds that visual and interactive aspects of medical information convey credibility in novel ways. At the same time, traditional sources of authority for medical information, such as science, are consistently important in signaling the credibility of the site and the information within it.

Chapter 6 explores the question of trust in the context of a patient support group. In an online patient community, trust is established in some similar ways as on the webpages, such as through the credibility of an expert moderator. However, trust is also established socially as peers disclose more information, identify points of commonality, and display an understanding of group norms.

Chapter 7, the Conclusion, summarizes findings and comments on how they contribute to the field of rhetoric and technical communication. It explains what the

findings mean for rhetoricians, technical communication instructors, e-health scholars, physicians, and web designers. I also suggest future research that could illuminate the issues raised in this dissertation.

Chapter 2: Literature Review

This literature review consists of two major sections that inform my study in different ways. The first section provides an overview of the broad field of e-health and its important aspects of peer support and patient ownership of data. In this section, I also describe the philosophy of patient-centered healthcare, which has influenced e-health and other fields. This background information is necessary for contextualizing my study, as well as for understanding the cultural influences and values that will shape the future of e-health.

The second major section summarizes the theoretical concepts I am using to examine the persuasion and interaction taking place within e-health sites: trust, ethos, and credibility, with trust as the overarching theoretical concept. Ethos, or a rhetor's projection of their character and credibility, is how the field of rhetoric typically addresses the issue of trust in communication: Ethos is employed by rhetors (in the case of my study, e-health organizations or contributors to an online support group) in order to gain the trust of the audience (e-patients). Literature on credibility from fields other than rhetoric is also helpful for understanding the rhetorical means of establishing trust in e-health sites. Though I am approaching this study as a rhetorician, I believe that the literature around trust, which is vast and multidisciplinary, can shed more light on the rhetorical dynamics of e-health sites than a focus on ethos or credibility alone can provide, as I will explain further. I also explain how trust became an especially relevant topic with the rise of the internet, then I address how the shift from webpages to the social web (also known as Web 2.0) adds new complexity to online trust.

Finally, I bring these two major sections together and address how questions of trust have been especially pertinent to e-health.

Background: E-Health

The term “e-health” has been used since the early 2000s to characterize the broad overlap between the internet and medicine. Eysenbach (2001) defines it as a field “referring to health services and information delivered or enhanced through the Internet and related technologies” (para. 3). He adds that e-health is not just about technical developments, but also represents a commitment to use technology to improve healthcare at all levels. While the topic of e-health is broad and interdisciplinary, it has been of special interest to internet studies, medical informatics, and public health scholarship.

E-health encompasses topics as wide-ranging as physician training, telemedicine, physician-patient e-mailing, electronic health records, online health interventions, and mobile health applications. E-health as a field has also been interested in ways that patients take initiative in their healthcare by searching the web for medical information and advice, whether from informational sites or online support groups. One of the reasons people go to the internet for health information or support is because their needs have not been met by other resources (Lee & Hawkins, 2010).

Consumers seeking health information online is not necessarily a new trend in e-health – it has become a well-established practice for patients to consult “Dr. Google” and go online for emotional support for a chronic disease. As Gurak and Hudson (2006) write, “accessing health-related information has never been easier than in the current ‘information age,’ as the Internet’s vast content and global reach allows health consumers to quickly connect with the latest information and expertise,” which has “leveled the playing field” between patients and physicians (p. 29).

As recent studies have shown, the internet is only growing as a resource for today's patients. According to the Pew Research Center, as of 2012, 72% of internet users had gone online for health information in the past year (Fox & Duggan, 2013). Another survey (Rankin, 2014) describes patient e-health research as "eclipsing" doctor-patient conversations: The average internet user spends 52 hours on e-health research per year and visits the doctor three times.

Med 2.0

Patients' use of the internet is changing both in quantity and in nature. They are looking beyond professional informational sites: About a quarter of e-patients use social media for health information, and about a fifth use Wikipedia (Rankin, 2014). The Pew study adds that 16% of adult internet users have used the internet to connect with others with similar conditions (Fox & Duggan, 2013). In sum, e-patients are not only seeking and consuming information. They are also engaging in more creative and participatory behaviors, such as inputting personal medical data to track and share with a disease community, interacting with others in a disease-specific discussion forum or social network, and composing and sharing narratives about health experiences.

This greater interactivity and patient involvement in e-health has been considered a feature of "Health 2.0" or "Med 2.0," terms which apply Web 2.0's emphasis on openness, personalization, and collective intelligence to medicine (Eysenbach, 2008b). (See the section "Trust and Web 2.0" for more about Web 2.0). Sarasohn-Kahn (2008) describes the concept of Med 2.0 as "The use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health" (p. 2). Like e-health, Med 2.0 does not

just denote the use of technology in a particular way, but also encompasses a broader attitude that values patient empowerment and responsibility (Eysenbach, 2008b).

To illustrate how Med 2.0 looks in practice, I will discuss two trends which evolved from classic e-health tools. First, online peer support is now taking more sophisticated forms such as medical social networking. Second, electronic health records, a tool traditionally limited to use in medical institutions, is now taking on new forms to reflect patients' ownership of their own medical data. I have chosen these two examples to discuss because they are predicted to be shaping forces in healthcare (Swan, 2009).

Online peer support

Face-to-face medical support groups have been around for decades. Even outside of formal groups, people have long been sharing their health experiences and advice with peers, family, and friends. And while in-person relationships remain an important resource for patients, many patients also consider online peers to be valuable parts of their support networks (Fox, 2011). Rheingold (1993) in his popular press book *Virtual Community* talks about how some of the earliest discussion groups on the web were devoted to medical issues.

As Fox (2008) found in a Pew national phone survey, patients still consider doctors to be experts in specific fields or conditions, but peers have an expertise that comes from simply being a patient: They are experts in how a condition or treatment impacts them individually, and can pool that knowledge with others. Likewise, Swan (2009) says that "a health condition is a particularly strong affinity and the collective learning and experience of others can be leveraged and shared to help individuals make decisions" (p. 495).

It has been well established that online support groups provide several benefits to members, such as emotional support, stress relief, enhanced communication with doctors, and coping strategies for living with disease (Bartlett & Coulson, 2011; Klemm et al., 2003; Rodgers & Chen, 2005), though the type of support offered within groups varies depending on the group and the condition. Some online support groups focus more on informational support (Coulson, 2005; Jaloba, 2009), while others balance that with emotional support (Mo & Coulson, 2008).

In comparison to face-to-face groups, online support groups can afford greater confidentiality and more connection to people in similar situations, and they are not as limited by time and space. Barak, Boniel-Nissim, and Suler (2008) comment on how the online medium for support groups can lead to greater disinhibition, with both positive and negative effects. For instance, anonymity can lead to greater feelings of trust and safety, because what participants share in the group context cannot be directly linked to their offline identity. This is particularly true for conditions that carry social stigma (Wright & Bell, 2003). Participants may also be encouraged to share more freely because computer-mediated communication lacks some of the status markers of face-to-face interactions. On the other hand, disinhibition may lead participants to more readily "flame" or disrupt group cohesion.[9] This disruption may have a gendered element in some contexts: Haas (2008), in a study of infertility support groups, found that men (at times physicians) tended to dominate and disrupt discussion. Other disadvantages of electronic support groups explored in the literature (Demiris, 2006;

[9] These questions about social cues, anonymity, and flaming in digital communication have been explored by early internet studies researchers (e.g., Kiesler, Siegel, & McGuire, 1984; Lea, O'Shea, Fung, & Spears, 1992; Turkle, 1995).

Wright, 2002) include delayed feedback, privacy risks, and lack of credibility, whether of information shared in the forum or of other members (for more information, see "E-Health and Trust" section).

While the earliest online medical support groups took place using listservs and bulletin boards, medical social networking sites and health information sharing sites have extended those early forms. Sites like CureTogether, PatientsLikeMe, and others mentioned in Chapter 1 have sprung up to provide a venue for sharing experiences and crowdsourcing medical information.

Patient ownership of medical data

Electronic medical records were originally (and are still) used to enhance communication and efficiency among insurance companies and healthcare institutions (Gurak & Hudson, 2006), but their role, in terms of audience and ownership, has been greatly shifting, with overall positive results for patients. According to Bleicher (2008), "The transfer of authority over medical records, although slow in coming, is a major step in patient empowerment" (p. 2). It is now quite common for patients to have access to aspects of their official medical records through electronic portals (Zarcadoolas, Vaughon, Czaja, Levy, & Rockoff, 2013). There have also been recent initiatives (i.e., OpenNotes) to share doctors' notes openly with patients (Feldman, Walker, Li, & Delbanco, 2013).

Some patients have been maintaining their own records using tools like HealthVault, WebMD Health Manager, and PatientsLikeMe. On some websites, medical profiles are publicly shareable. The goal behind this transparency is that electronic medical records be more than just "a static repository" to be used only to enhance patient-physician communication; ideally, they "should combine data, knowledge, and

software tools to help patients become active participants in their own care" (Frost & Massagli, 2008, para. 2).

Along with patient access to and ownership of their health records, the act of quantified self-tracking, popularly known as "the quantified self" (Wolf, 2009), reflects the value of patient ownership of data. Swan (2009) observed the growing interest in self-tracking in the medical realm: "[I]ndividuals are starting to measure, track, experiment, intervene, treat and research their conditions and symptoms, genomes, biomarkers, behavior and environment, both individually and in collaboration with others" (p. 512). The quantified self-tracking movement includes physical devices and sensors such as wireless scales or pedometers that automatically track relevant health statistics – a health-focused application of the larger trend of the "Internet of Things." Some patient advocates have even argued, in the name of patient empowerment, that self-tracking should be available with telemedicine devices such as defibrillators, which as of now only transmit data to the physician (Krieger, 2012).

These Med 2.0 tools – online peer support and patient-maintained health data – reflect values such as empowerment, agency, and collaboration that are shared by the patient-centered healthcare movement. Like the subject of e-health, patient-centered healthcare is of interest to multiple disciplines, though it tends to be discussed in the public health and medical fields. I will now broaden out to explain the movement generally, in order to better situate e-health.

Patient-centered healthcare

Traditionally, physicians have held the dominant role in the patient-physician relationship, serving as gatekeepers and medical decision-makers, while patients have held more passive and dependent roles (Dickerson & Brennan, 2002). In contrast, with

the model of patient-centered healthcare, a concept also captured in phrases like "patient-driven care," "patient autonomy," "patient agency," "shared clinical decision-making," and "participatory medicine," patients are encouraged to become active participants in their care. In this model, physicians take on a role more like that of a guide or advisor, while patients take on more responsibility for their own health, shifting "from being a minimally-informed advice recipient to an active participating, instigating collaborator, information sharer, peer leader and self-tracker engaged in participative medicine" (Swan, 2009, p. 513). According to a survey conducted by the Institute of Medicine (Alston et al., 2012), most patients desire this kind of deep engagement with their healthcare and this kind of collaborative relationship with their physicians; however, actual implementation of shared-decision making in the United States is low. Nonetheless, healthcare has come a long way in terms of informing and involving the patient.

A series of changes across the 20th century set the foundation for more patient-centered healthcare, including lawsuits clarifying the need for informed consent, the 1947 publication of Dr. Spock's *The Common Sense Book of Baby and Child Care,* the feminist movement in the 1970s, and insurance companies' efforts to drive down healthcare costs (Millenson, 2011). Finally, the internet and Web 2.0 have both supported and been shaped by the movement. As discussed above, it is now quite common for patients to actively seek information about their conditions and options and bring that knowledge to the doctor-patient encounter.

Certainly, the role of the internet in lessening hierarchy within the doctor-patient relationship is no small change and has generated concerns among members of the medical community (and more broadly). As Kopelson (2009) writes, e-health "has blown

away the doors of the locked library to render medicine's official disciplinary discourses available to greater scrutiny" (p. 391). As a result, e-health researchers have been interested in the appropriate role of internet information in the doctor-patient relationship. Many scholars point out that a beneficial doctor-patient relationship will involve the doctor guiding the patient to valuable information and working with the patient to come to the best decision, rather than disregarding a patients' personal research or data collection. Al-Ubaydli (2012) says that Med 2.0 technologies are enabling a "quiet revolution" in the patient-physician relationship in which both parties bring their experience and knowledge to bear on medical decisions.

Scholars in medical rhetoric and technical communication have also been interested in the power dynamics of medical contexts and have focused particularly on how writing can reflect and influence agency. For instance, Segal (2005) in *Rhetoric of Health and Medicine* argues that rhetoric as a field can bring important insights to medicine, which, due to its close alignment with science, has often been seen as a-rhetorical. Throughout her book she reveals how persuasion operates in a variety of texts ranging from medical textbooks to patient-authored pathographies, a genre which aims to give patients a voice and to highlight the experiential versus the medical aspects of an illness. Other scholars have explored how official medical texts can limit patient agency (Stone, 1997; Teston, 2009). More recently, rhetoric and technical communication scholars have been looking at questions of power and agency in a wider range of medical texts, such as in informal online communication (Bellwoar, 2012; Haas, 2008).

Rhetoricians Segal (2009) and Kopelson (2009) critically examine the narrative of the empowered e-patient. In a rhetorical analysis of medical editorials written by

doctors, Kopelson found that e-patients were constructed in a variety of ways: as "cyberchondriacs," victims of misinformation, empowered but demanding, or teachable. Interestingly, she also identified a tendency to view today's "empowered" e-patients as resources to be exploited, taking on the burden of research that typically falls within the province of doctors.

The questions about power and agency that rhetoric and technical communication scholars have been addressing also figure into questions of credibility and what counts as expertise. As Hartelius (2008) writes, doctors have enjoyed an inherent credibility: "Few experts have as much direct influence over the general public as medical doctors. Few enjoy the same level of esteem and approbation" (p. 103). But today, she argues, there exists a tension between various sources of expertise: Patients draw on lived, bodily experience as the source of their expertise; doctors draw on scientific knowledge as the source of their expertise. Kopelson (2009) suggests that many of the arguments for quality control within e-health are boundary-keeping moves by the medical profession, "an alarmed (sometimes alarmist)" reaction to "the democratization, demystification, deprofessionalization, diversification and pluralization of medical knowledge generated by the internet" (p. 354).

Indeed, much of the scholarly work on the quality of e-health information, from a variety of fields, reflects the broader unease with the internet's lack of the traditional gatekeeping and quality controls associated with print. Trust, as a theoretical frame, can help explain the issues of how people navigate this information online and the rhetorical features that guide them. Therefore, I will now address research on trust, first in a general sense, then as applied to the internet and Web 2.0. This in-depth look at

trust will inform the final section of my literature review, in which I summarize literature intersecting trust and e-health.

Theoretical Frame: Trust

A Note on Terminology

When I began research, I found that trust, ethos, and credibility were the predominant theoretical concepts, used in various fields, to characterize the broad issue of how users choose to trust websites and information online. My initial approach was to interpret these three ideas in an open-ended way, in order to gain a more comprehensive picture of the rhetorical dynamics in e-health sites. I found that the terms are not used consistently across the literature. In fact, many articles attempting to outline taxonomies and definitions were motivated by a recognition of the ambiguity of the terms. Clearly, the breadth of work on each of these complex topics makes it impossible to pin down one "correct" understanding of what they mean and how they are related, and that is not my goal. However, as I progressed through the analysis, I found that I have been understanding and using the terms in particular ways. I will lay that out briefly now, followed by a more thorough summary of the ways scholars have conceived of the concepts.

I see trust as a concept that encompasses ethos and credibility, yet is broader than they are in that trust indicates an act, a "leap of faith" or "bet on the future," as some have described it (e.g., Bargh & McKenna, 2004; Sztompka, 1999); ethos and credibility are rhetorical means of gaining the trust of others. As Walther, Wang, and Loh (2004) put it, "credibility is not and end-goal in and of itself, but a facilitator of persuasion, attitude, and behavior" (i.e., trust) (Discussion section, para. 10). I follow Aristotle's understanding of ethos because it most closely matches the dominant

perception and is the starting point to which most other understandings of ethos are compared. So, when I use the word ethos, I am referring to a speaker's (or organization's) projection of character and credibility.

Credibility has been used to refer to the believability of a speaker as well as of information. When used to refer to a speaker, credibility has been equated with ethos, because both consist of qualities like intelligence, expertise, competence, sincerity, honesty, and reliability, and both play an important role in whether an audience trusts a speaker. When used to refer to information, the term credibility tends to focus on aspects such as the accuracy and objectivity of information.

Following these understandings from the literature, as reflected in my chapter titles, the term *ethos* will feature more prominently in Chapter 4 when I am talking about credibility in the organizational information pages, since these main pages constitute the organization's identity and values much more obviously than the medical information pages do. The analysis of medical information pages in Chapter 5 draws more on the body of literature on *information credibility*. Chapter 6, because it investigates a patient forum, draws chiefly on literature about *trust* and online community. Despite these different emphases, it should be noted that ethos, credibility, and trust are present across all the analysis chapters and all ultimately link back to how *trust* is established in e-health sites.

Now that I have offered some brief distinctions in my understanding of the terms, I will move on to a discussion of ethos, which is the primary theoretical construct through which scholars in rhetoric have addressed trust.

Ethos

Ethos in classical and modern rhetoric

The word *ethos* essentially means *character* in Greek. Ethos has been called one of the most durable concepts from rhetorical theory, having been used in fields ranging from philosophy to composition to literature and, more recently, communication on the internet (Bruss & Graff, 2005). As the variety of disciplines suggests, ethos has been defined and adapted in numerous ways. In light of this diversity, Aristotle's definition of ethos is a helpful starting point.

In the *Rhetoric,* Aristotle (2007) used the term *ethos* to refer specifically to the character of the speaker as a mode of persuasion. And, while there were antecedents to Aristotle's theory of ethos, such as references to the speaker's character in the *Iliad* or in Plato's *Gorgias* (Fortenbaugh, 1992), Aristotle was the first to place ethos within a systematic framework of persuasion, alongside of *logos* (or reasoning in the speech) and *pathos* (or the emotional state of the audience). These three *pisteis*, or proofs, formed the foundation of rhetoric for Aristotle, which he defined as "an ability, in each [particular] case, to see the available means of persuasion" (p. 37).

In the Aristotelian conception, persuasion through ethos takes places "whenever the speech is spoken in such a way as to make the speaker worthy of credence; for we believe fair-minded people to a greater extent and more quickly [than we do others]" (p. 38). He saw that *pisteis*, or belief (or trust), results from "speech that reveals character (for we believe the speaker through his being a certain kind of person, and this is the case if he seems to be good or well disposed to us or both)" (p. 74). These quotations suggest that ethos consists of multiple qualities; Aristotle breaks them down into 1) practical intelligence or wisdom, 2) virtue, and 3) goodwill (p. 112). Miller (2003) draws

attention to the communal nature of ethos when she summarizes Aristotle's definition as "the character of the persuader understood against the character and conventions of the culture" (p. 167).

Ethos is particularly important in cases where there is not precise knowledge. Since all rhetoric deals with uncertainty, this makes ethos, according to Aristotle (2007), the most authoritative of the three modes. As Corbett and Connors (1998) write, "all of an orator's skill in convincing the intellect and moving the will of an audience could prove futile if the audience did not esteem, could not trust, the speaker" (p. 19). For Miller (2003), because we rely on ethos in the absence of other modes, it could be considered the "default" mode of persuasion.

To Aristotle, ethos is strictly artistic, meaning that aspects such as the speaker's prior reputation would not fall within the definition of the proof through ethos. Kennedy, translator of Aristotle (2007), speculates that this was because in ancient Greece many speakers in courts or the Assembly would have been unknown to the jury or audience (p. 39). Other theorists have taken issue with this limitation of the concept to artistic or invented ethos, and have expanded ethos to encompass reputation (or situated ethos, in Crowley & Hawhee's (2004) terms). For instance, Isocrates (1990) wrote, "The man who wishes to persuade people will not be negligent as to the matter of character… for who does not know that words carry greater conviction when spoken by men of good repute than when spoken by men who live under a cloud" (p. 52). While prior reputation does contribute to persuasiveness, what is said within the speech itself has the power to influence that reputation (Corbett & Connors, 1998).

Closely related to the matter of reputation is the question of whether a rhetor's ethos results from *actual* character or whether it is merely the *projection* of good

character. According to Kennedy in his 2007 translation of Aristotle's *Rhetoric*, "the role of character in a speech is regarded as making the speaker *seem* trustworthy" [emphasis mine] (p. 38). Bruss & Graff (2005) explain that "Aristotle is not particularly interested in the speaker's actual or genuine character but rather in the artistic presentation of the sort of character that will be persuasive to the audience he is addressing" (p. 42).

Again, other rhetoricians have taken a more expansive view of the persuasive role of character, linking it more clearly to genuine character. Quintilian, for instance, defines a rhetor as "a good man speaking well." Gurak (1997) explains, "it is not just the projection of the character or a speaker or group, but also his (or her, or the group's) actual moral and ethical character that is relevant to both the effectiveness and the quality of the speech" (p. 14).

In summary, ethos has been interpreted in at least two main ways: There is the Aristotelian "in the speech only" conception and Quintilian's "good man" conception. Ethos has been interpreted in yet another way, based upon tracing the word back to its etymological roots as "a habitual gathering place" (Halloran, 1982, p. 60). Sullivan (1993) links this meaning to Kenneth Burke's consubstantiality, conceiving of ethos as negotiated between speaker and audience rather than as a static quality.[10] Likewise, Warnick (2007) talks about ethos as embedded in cultural mores, and Gurak (1997) addresses how this understanding of ethos applies to online spaces – internet users

[10] A classic example of Burke's (1969) theory of consubstantiality or identification is the politician saying, "I was a farm boy myself" (p. xiv). This notion of likeness is especially pertinent in many patient-participatory sites, such as the website title *PatientsLikeMe* or WebMD's advertisement of finding "others like you" in its communities.

take on a group or community ethos by spending time within an online community and learning its norms.

This emphasis on community values expands ethos from its classical grounding in the speaker's character (as in moral virtue), to being viewed as a set of qualities that describe the speaker, or a persona. A persona is persuasive to the extent that the audience recognizes and shares the values that the rhetor projects. Halloran (1982), in discussing the persuasive scientific ethos of Watson and Crick, defines ethos as "a characteristic manner of holding and expressing ideas" (p. 71) and as "a recognizable public persona" (p. 75). Sullivan (1996) describes ethos as a persona that creates trust and indicates membership in a group or community.

This communal view also broadens our understanding of ethos from characterizing only individuals to also characterizing a group, organization, or even a culture. For instance, Gurak (1997) found in her study of online protests that the angry, personal ethos of the protesters as a group contributed to their success, because the group's ethos appealed to the shared values of the community of early internet privacy advocates. Hence, although classical ethos centered on an individual speaker in the context of a formal public address in a physical location, ethos in contemporary times has been used to help explain persuasive dynamics in broader contexts and to describe the characteristics and qualities of a rhetor.

Ethos in websites

Ethos is an especially valuable tool for understanding persuasion in digital environments, because digital environments enable users to control the presentation of their identity in distinct ways. Website designers, corporate public relations

departments, and participants in online communities are able to make textual and visual choices that persuade others towards trusting them.

Within the field of technical communication, researchers have drawn on classical rhetoric and ethos for strategies for evaluating, designing, and revising websites. For instance, Hunt (1996) distinguishes between web designers' choice of conveying a traditional, professional ethos, or a communal ethos that emphasizes common values between the website creators and their audiences. Brock (2012) analyzes the official ethos conveyed by proprietary software websites compared to the more participatory ethos of open source software websites. Coney & Steehouder (2000) and Swenson, Constantinides, and Gurak (2002) discuss the importance of a trustworthy online presence (ethos) and of understanding the audience's values and needs. Spoel (2008), in her analysis of Canadian midwifery websites, equates ethos with an organization's "identity and value" (p. 267) and pays particular attention to the relationship the midwifery organizations constructed with their audiences. As these examples from technical communication suggest, ethos on websites is often conveyed through values and relationship.

In summary, while classical to modern rhetoricians have debated the particulars of ethos, a commonly accepted facet of ethos is that it has to do with the character of the speaker; in other words, it is linked to identity, whether of an individual, organization, or community. Likewise, technical communication scholars have defined ethos, in terms of web design, as an organization's persona or presence. For my purposes, I use the word ethos to refer to the rhetor's projection of their character and credibility.

Ethos and visuals

Traditionally, rhetoric as a field has focused on texts. However, visual elements of websites, alone and in tandem with text, can also be powerfully persuasive, especially in medical contexts. Work in visual rhetoric, then, is helpful for understanding how visuals can be used rhetorically to contribute to trust on e-health websites. In this section, I will review work on ethos and visuals generally, then explore a couple of research areas which are particularly relevant to e-health sites. Because some of the newest e-health sites are centered on the sharing and visualization of data, I will review rhetoric and technical communication scholarship on data visualizations, in print and online contexts. Quite recently, internet users have found themselves able to generate, access and display datasets in new ways. At a large scale, some have called this proliferation of information "big data," which some scholars have argued has a persuasive sense of objectivity all its own, due to its quantity and the ability of computerized methods to aggregate, visualize and identify patterns in it. Rhetoricians have not explicitly and extensively drawn connections between ethos, big data, and data visualizations, but I address these connections here because they provide insight into how some e-health sites build credibility.

In the opening to their 2004 edited collection, Hill and Helmers (2004) acknowledge the difficulty in defining visual rhetoric. Works like theirs are helpful for showing the range within the subfield of visual rhetoric: both of artifacts (like photographs, political cartoons, charts or data displays) and of theoretical frames (like Perelman and Olbrechts-Tyteca's rhetorical presence or Aristotle's ethos). In this book, authors give examples of visual ethos such as an image of the Whitehouse in the background of a news broadcast, lending governmental authority to a reporter's words,

or actors in white lab coats with stethoscopes that convey physician or scientist authority in a drug advertisement.

Hutto (2008), in an article comparing the graphics used in two biomedical journals, states that medical research almost universally represents information via both text and graphic. Because a scientist's ethos is so important, he argues, it is valuable to study how graphics support that ethos. He includes a helpful literature review of scientific and medical ethos and graphics, showing how historically, scientific imagery has contributed to credibility because of its semblance of reality and objectivity. In his own analysis, he identifies credibility appeals in graphics such as goodwill, shown by adding features to charts to make them easier to interpret, or giving complete information to show precision and experimental competence. Lending more support to the persuasive value of visuals, researchers in applied economics found that, in a series of experiments, participants considered claims about drug effectiveness to be more credible and persuasive when those claims were accompanied by graphs, regardless of the actual quality of the data or the effect of the graph on improving comprehension. The researchers concluded that graphs "grant a halo of scientific validity" just by virtue of appearing scientific (Tal & Wansink, 2014, p. 2).

In terms of visual ethos, scholars in rhetoric and technical communication have also addressed how aspects such as typography choice (Brumberger, 2004) or whole-document design (Kostelnick, 1996) can affect readers' perceptions of writers' professionalism. Brumberger (2010), in an analysis of Medicare documents and webpages, discusses how seniors (the primary audience of Medicare documentation) have particular usability needs as they use documentation to guide decision-making.

She emphasizes that document and web design contributes to readers' perceptions of an organization's ethos and its concern for their audience.

Kostelnick (2007) has done some work on data visualization that is helpful for making sense of how online data displays, drawn from large datasets, can be considered credible. He argues that the rational, efficient rhetoric used in data design is the visual parallel of the Shannon-Weaver "transmission" model of communication and is shown today in well-known information design writer Edward Tufte's maxims for precision and clarity in data displays. Kostelnick addresses the challenges of conveying ethos in data displays. For instance, designers might use a 3D display, hoping to increase sophistication, but in fact weaken their ethos by impeding the reader's ability to make clear comparisons. This example serves as just one reminder that there is no precise rule for how to accomplish rhetorically effective, clear, and precise data design. Wolfe (2009) complicates Kostelnick's argument somewhat, suggesting that Tufte's maxims for clarity and precision are still useful, especially for students training for professions that explicitly value those criteria (such as engineering). In her survey of technical communication textbooks, she touches on how things like using the correct type of graph can enhance a student's or employee's ethos – help them appear as competent within a disciplinary community.

As both Kostelnick (2007) and Rawlins and Wilson (2014) argue, data displays are proliferating online and are growing in complexity and interactivity, and this needs to be accounted for in research. Other scholars (Kim & DiSalvo, 2010; Sorapure, 2010) say that information visualization is an important feature of Web 2.0 that helps internet users make sense of the "deluge" of information once available only to scientists, engineers, or government entities. Sorapure also notes, "We are less likely to question

the authority of data or to see the potential biases in how it was gathered, organized, and visualized" (p. 61), pointing to an inherent sense of transparency and credibility in data and its visualization, which may not correspond to reality.

This deluge of data that is now available for analysis has been casually referred to as "big data." Internet studies researchers boyd and Crawford (2012) put forth a highly-cited definition of big data as essentially the use of technology to analyze "massive quantities of information produced by and about people, things, and their interactions" (p. 663). Importantly for them, big data is also characterized by mythology: "the widespread belief that large data sets offer a higher form of intelligence and knowledge that can generate insights that were previously impossible, with the aura of truth, objectivity, and accuracy" (p. 663). Their article is principally a critique, reminding analysts to consider important questions about access, accuracy, and unforeseen consequences, particularly when data is derived from social network sites. Lyon (2014) likewise argues that collection of big data reflects faith in technology. His article looks at larger issues such as the role of social network data in government surveillance. And Lehikoinen and Koistinen (2014) also point out that while big data "may change in many ways our core understanding of the world," it should not be blindly trusted (para. 20). The above authors, while not within rhetoric per se, share rhetoricians' goal of bringing a human and critical element to what has come to be seen as an objective, data-driven way to bring order to the complexity of the world.

From directly within rhetoric and technical communication, some scholars have made similar arguments, though have not discussed big data extensively. As Salvo (2012) writes, big data "brings data visualizations together with large databases and presents relationships existing deep within the data…And they work, capturing

attention and testifying to the power of revealing systematic relationships" (pp. 37-38). Others in technical communication have been thinking about big data and methods (Graham, Kim, DeVasto, & Keith, 2015; McNely, 2012), for instance, how to merge a human, qualitative perspective with statistical analysis of big data.

Credibility

In rhetoric, ethos addresses a speaker's projection of their character and credibility, but the concept of credibility has been thoroughly studied in other fields like psychology and communication. The topic began to receive special attention surrounding WWII, in an effort to better understand propaganda. Out of this time period emerged a definition of credibility that is still generally accepted, that credibility consists of two qualities: expertise (competence, intelligence, etc.) and trustworthiness (which is taken to mean warmth, sincerity, honesty, reliability, etc. – connected to character) (Hovland, Janis, & Kelley, 1953). Scholars in computer science (Fogg & Tseng, 1999) as well as in professional communication (Mackiewicz, 2010) have adopted this understanding of credibility.

Mackiewicz (2010), in her study of credibility construction in online reviews, provides examples of how the different dimensions of credibility contribute to the ethos of reviewers of online digital cameras. A reviewer, genuinely trying to be helpful, might post a very detailed review of a camera. However, in misunderstanding some key technical features of the camera, he would reveal his lack of expertise, thus damaging his credibility. Conversely, another reviewer might post a positive and technically accurate review, demonstrating expertise with digital cameras. Yet, if she is employed by the camera manufacturer, she might be perceived as insincere and untrustworthy, thus damaging her credibility. Another example of this two-part view of credibility

comes from a study of public opinion of scientists (Fiske & Dupree, 2014). The researchers found that the public *respects* scientists as experts, but does not necessarily *trust* them as warm and sincere.

According to Flanagin and Metzger (2000), this understanding of credibility guided credibility research in psychology and communication that focuses on "*source* credibility, typically conceptualized as the believability of a speaker and closely aligned with Aristotle's notion of ethos," whereas "Research in the field of information science has focused instead on the credibility of information, where the emphasis has been on believability of messages rather than speakers" (p. 211).

To summarize, credibility can, in some contexts, be synonymous to ethos: They consist of similar qualities and are instrumental in establishing the trust of audiences. However, credibility can also refer to features of information, such as accuracy and objectivity, not necessarily linked to a speaker's character. When rhetoricians talk about credibility, they are typically referring to how speakers project their character and credibility in the larger context of persuasion (and their methods tend to involve close attention to the speech, text, or, in my case, website, and how its ethos works persuasively (or not)); when scholars in fields like information science, computer science, and communication talk about credibility, they are typically interested in things like the objective accuracy of information or the processes and criteria by which audiences assess credibility (and their methods tend to involve experiments, interviews, and surveys). Across these different fields, scholars are talking about the same thing but asking different questions about it; these other perspectives inform how credibility is used persuasively in e-health sites.

Trust

I have explained ethos and credibility, the rhetorical means by which e-health organizations attempt to establish trust online. However, as mentioned before, I see trust as broader and therefore perhaps better able to explain the dynamics of e-health sites, particularly in the most interactive spaces. Basic definitions of trust center on the notion of belief – internet studies researchers Dutton and Shepherd (2006) define trust as "a confident expectation" (p. 434), and Boyd (2003) calls trust "a belief in an agent's competence, predictability, integrity and benevolence" (p. 398). Fogg and Tseng (1999) define trust as "a positive belief about the perceived reliability of, dependability of, and confidence in a person, object, or process" (p. 81). In other words, while credibility characterizes a *quality* (and ethos is the speaker's projection of that quality), trust is an act, a *belief*, that may involve more than just a rhetor's successful presentation of their credibility and character. For instance, someone might look at a governmental website, a website that by all accounts has constructed a successful ethos that conveys the credibility of their information and the people behind it. Yet, that user may not trust it. Perhaps that person is inherently distrustful, or considers information from their peers to be inherently more trustworthy because it is based in real-life experience.

And, one does not necessarily need to perceive another as credible, or be able to trace their true identity, in order to trust them. Some research on trust has helped illustrate this complexity. In her research on early online activism, Gurak (1997) found that participants often trusted each other without knowing the identity and character of the rhetor. This trust was facilitated by a sense of community online. Likewise, in their study of virtual teams, Jarvenpaa, Knoll, and Leidner (1998) found that successful teams exhibited swift trust, or acted as though trust was present from the start.

Originally studied in the context of temporary work teams, swift trust is associated with a deep focus on the task at hand, in contrast to how trust typically develops – gradually over time.

While trust is somewhat mysterious in terms of how it works, scholars consider it "a functional prerequisite for the possibility of society" and "indispensable in social relationships" (Lewis & Weigert, 1985, p. 968). According to sociological perspectives, trust is characterized by vulnerability – people take on vulnerability or risk when they make the choice to trust. As I mentioned before, some have described it as a "leap" or "bet." In other words, trust is about belief but also involves an orientation to action (Henderson & Gilding, 2004). The condition of vulnerability makes trust especially critical to interaction in online spaces, in which identity presentation, community norms, and security risks complicate users' decisions to trust. German sociologist Luhmann (1979) did some early work of conceptualizing trust in his treatise *Trust and Power*. He notes that trust, or "confidence in one's expectations" of the world, is necessary for even "getting up in the morning" (p. 4). Trust is a mechanism for reducing the complexity and uncertainty in the world. "Where there is trust," he writes, "there are increased possibilities for experience and action" (p. 8).

While Luhmann was obviously not writing in the age of the internet, his statement applies to online settings: Online, a user cannot ascertain all of the risks of an exchange or exhaustively assess the truth or falsity of online information, and therefore must decide whether to trust in the absence of complete knowledge. Given this understanding of trust as a mechanism for reducing complexity, it makes sense that it has been a hot topic in discussions of the internet, where people have been pondering how to respond to seemingly infinite amounts of information. Accordingly, trust (both

face to face and online) has been an important research topic across several fields, and seems a logical way to define the problem this dissertation addresses.

It is not surprising that there has been confusion surrounding attempts to define trust. Wang and Emurian (2005) attribute the multiple definitions of trust to the abstractness of the concept, the fact that it is "used interchangeably with related concepts such as credibility, reliability, or confidence" and that it incorporates "cognitive, emotional, and behavioral dimensions" (p. 108). Different disciplines conceive of trust in their own ways. For example, psychological perspectives tend to view trust as a personal, individual feature intrinsic to the trustor, social psychological perspectives tend to view trust in the context of interpersonal relationships, and some sociological perspectives have emphasized trust as a group or institutional property (Beldad, de Jong, & Steehouder, 2010). For my purposes, given my interest in the social web for e-health, a view of trust as *social* is especially enlightening for understanding the peer-to-peer aspects of e-health. A social view of trust recognizes the importance of "closeness, intimacy, and familiarity" in establishing trust (Sztompka, 1999, p. 81). Overall, drawing on the basic understandings of trust reviewed above, I see trust as an expectation or belief (in an individual, organization, or website) that is confident enough that one would be willing to act on it, placing oneself in a position of vulnerability.

In work that addresses online trust, trust and credibility are often discussed in tandem because of the close relationship between someone's assessment of an individual or information as credible and their choice to trust it. The next section describes how trust has been addressed in online settings, and why the online setting complicates it.

Trust online

Trust is formed differently online than in face-to-face settings for a number of reasons. As the earliest researchers in computer-mediated communication found, a screen name and language choices can only communicate so much information about one's identity; without the in-person cues that traditionally help one form an impression of another, credibility assessment becomes more challenging (Hiltz & Turroff, 1978). The story of "Joan" has been used to exemplify the problem of trust and identity online. Van Gelder (1990), in her essay "The Strange Case of the Electronic Lover," tells the story of Alex, a New York psychologist who created the false online persona of Joan. Joan had supposedly been disfigured in a car accident and pursued close friendships, and ultimately intimate relationships, with multiple women online. According to Van Gelder, the revelation of Alex's true identity created a deep sense of shock and betrayal among those who knew Joan. Turkle (1995) has also theorized about the decentered, multiplied, uncertain nature of identity in digital settings such as MUDs (Multi User Dungeons).

Another complicating factor in online trust is the addition of risks that are not present in face-to-face settings: Computers introduce the possibility of problems such as security failures and data misuse (Boyd, 2003). Additionally, the nature of information on the web complicates trust: Due to speed and reach, misinformation can spread faster and farther online than before, and anonymity lessens accountability for creating and spreading it (Gurak, 2003).

Furthermore, the interactive nature of the internet has opened up the process of knowledge creation to many more users. With the internet as a bottom-up medium, there is little, if any, gatekeeping or review of content as in traditional journalism.

Consequently, there is potential for more false or low-quality information on the internet and the burden to evaluate it lies with the reader.[11] As Warnick (2007) writes, evaluating the credibility of print information was simpler: One could more easily look to the source or author of the message, and his or her expertise and reputation. However, the frequently anonymous and distributed nature of authorship on the web renders impossible, or at least complicates, the process of externally verifying a source's credentials, as with modernist notions of credibility. Even Aristotelian ethos, Warnick reminds us, relied not upon external knowledge of the rhetor, but upon the rhetor's construction of himself as credible within the speech.

The problem of misinformation and the challenge of authorship on the web has led to a proliferation of guidelines for credibility assessment of websites and online content that often fall under the rubric of "digital literacy." Digital literacy education is of interest to multiple fields, such as information science, healthcare, and of course composition and rhetoric. Credibility guidelines published by educational institutions often include categories such as authorship, currency, links, accuracy, and design (Gurak, 2003). Another study (Metzger, 2007) labeled similar criteria such as "accuracy, authority, objectivity, currency, coverage" as the commonly-taught "checklist" for credibility assessment in schools.

However, as Burbules (2001) argues, traditional means of credibility assessment online, such as looking at the expertise, currency, or bias in a source, fail to

[11] Of course, books and other print works are not inherently more trustworthy than online content by virtue of being printed: Adams and Berg (2004) look back to the history of the book to deconstruct the common perception that the printed book is a "bastion of trustworthiness" in contrast to the "renegade" web. They argue that the printing press, which enabled the publication process to bypass the traditional gatekeeping function of the church or the courts, was met with many of the same concerns about misinformation and unverified authorship that the internet has been met with today.

acknowledge the ways people actually use the internet – often quickly and with varied goals in mind. Moreover, traditional guidelines fail to acknowledge the unique challenges of online information – its sheer volume, the ability of misinformation to spread quickly, and how the web can operate as a closed, self-supporting reference system. He introduces the idea of "distributed credibility," which recognizes credibility not as the objective assessment of the truth or falsity of a source, but as dependent on individual and community values (p. 450).

Later internet scholars would echo and expand upon Burbules' argument for a more contextualized, complex understanding of credibility on the web, especially in response to the rise of social networking and user-generated content, two aspects of Web 2.0. Before exploring those perspectives on the role of the social in credibility assessment, however, it is important to understand how the term "Web 2.0," sometimes referred to as the "participatory web," has been used. An understanding of the nature of the participatory web is also helpful for contextualizing e-health sites that are moving in more participatory directions.

Trust and Web 2.0

When I talk about the shift from more static webpages to the social web, I am referring to a shift that others have labeled "Web 2.0." While the term "Web 2.0" may seem dated, it does work to characterize the gradual shift from passive consumption of the web to greater participation and contributions by users, enabled by tools like wikis, blogs, and social networking ("Web 2.0," 2014). Wikipedia and Facebook are iconic examples.

The term Web 2.0 became popular in the early 2000s as a way to describe the web's new emphasis on collective intelligence, openness, transparency, and sharing.

As Antonijevik and Gurak (2009) write, though, these activities and features of the internet are not new so much as magnified by Web. 2.0: "Web 2.0 has made visible what has always been there – engaged users and engaged online communities." Even before the web, the earliest computer networks afforded the creation of community. As far back as the 1960s, electrical engineers Licklider and Taylor (1968) anticipated online interactive communities "not of common location, but of *common interest*" (p. 38). Nevertheless, Web 2.0 tools have opened participation to greater numbers of users, making participation a defining feature of the internet today. Now, social networking is practically ubiquitous among internet users, and Wikipedia is a major reference site on the internet.

In line with the growth of collaborative, social websites, studies of internet users also highlight a social dynamic in credibility assessment and the decisions of what to trust online. Recent empirical studies show that internet users are relying increasingly on peers compared to traditional authorities[12] (Jessen & Jørgensen, 2012). As an example, in the case of the North Minneapolis Post Tornado Watch, people trusted a Facebook page, created by a local, more than they trusted official government sources (Gurak, 2014). At any rate, author credentials, authority, and expertise are not necessarily the primary criteria by which users choose to trust online (Warnick, 2004). Or, at the very least, users are not assessing those criteria in the ways commonly expected for the print age.

[12] While not examining the context of the internet specifically, the Edelman Trust Barometer (2012) found that, as of 2012, the public's trust in government officials and CEOs had dropped. Meanwhile, trust in peers rose, leading the researchers to conclude that "People now trust one another more than they do established institutions" (para. 4).

As a result, Jessen and Jorgensen (2012) argue that earlier conceptions of credibility, such as the model described above that divides it into expertise (intelligence) and trustworthiness (sincerity, honesty), may be inadequate. For instance, on wikis and social media, direct cues of authorship or expertise are few if not absent. In lieu of these cues, many users rely upon social feedback and collective judgment (for instance, ratings and "likes") to help them assess the credibility of a source. Even the navigation process can provide users with credibility information by filtering or highlighting search results based on users' previous online actions. Providing further support for the social and multi-layered nature of credibility assessment, other studies have suggested that, in contexts like Twitter, verified account status, Twitter bios, and who retweets or recommends a news story can affect perceptions of credibility (Jiang, Tong, & Tan, 2012; Schmierbach & Oeldorf-Hirsch, 2012); visualizing for users how popular a website is, especially among those considered "expert searchers," can also affect credibility perceptions (Schwarz & Morris, 2011).

In other words, recommender systems, ratings, and other computerized systems that take into account user habits and peer opinions can play an important role in inducing trust online. According to Eysenbach (2008a), "On a decentralized, electronic medium, peers and intelligent systems can give consumers additional information about a topic from other sources and perspectives, which can mediate (reduce or enhance) their trust in a message in a personalized, tailored way" (p. 129). Jessen and Jorgensen (2012) offer WikiTrust as an example of a computerized algorithm that has harnessed social validation to increase trust. This browser add-on color-codes Wikipedia text based on frequency of revisions. It presumes that the longer an edit has persisted, the more people have approved of it, thereby increasing its

credibility. Related examples include vandalism-detection metrics to help Wikipedia increase its credibility (Priedhorsky et al., 2007) and algorithms for inferring trust relationships in a social network (Golbeck & Hendler, 2006). Gurak (2014) observed how incorporating tools like "data mining, recommender systems, behavior matching, demographic and giving patterns" into a political campaign increased trust and aided its success (p. 13).

Credibility assessment relies upon a patchwork of many factors and information sources that individually may not appear credible, but that when verified by many people, "spread out the risk" of relying on just a few sources. Taking these newer means of credibility assessment into account, Jessen and Jorgensen (2012) propose a model of "aggregated trustworthiness." Reminiscent of Burbules' (2001) "distributed credibility," this model incorporates social validation and navigation processes.

A study by Warnick (2007) further illustrates how credibility operates differently on the web today. She rhetorically analyzed the site Indymedia, which differs from corporate, mainstream news sources in that it enables anonymous users to post news stories. Warnick found that Indymedia emphasized values such as free speech and openness and explicitly positioned itself in contrast to the values of mainstream media (e.g., quality control, identifiable authorship) that align with more traditional credibility criteria. In her analysis, Warnick draws upon Toulmin's notion of field-dependency to emphasize that credibility evaluation depends on context and on a website's or organization's shared values with their audience.

Collectively, this research on trust in the age of Web 2.0 adds new dimensions – social validation, collective judgment, and community values – to earlier conceptions of web credibility based upon conventional contributors to credibility such as expertise.

This is not to say that expertise and authority play no role in credibility assessment; these studies merely highlight the need for any analysis of the credibility of a website or an online community to consider how distinctly social elements and even the search and navigation process can contribute to trust online. This broader, more dynamic view of web credibility is particularly helpful for understanding why sites like Wikipedia or Twitter, or online discussion forums, can still be seen as trustworthy to users, despite their lack of verifiable authorship or information review processes.

Trust in websites

Based on the above, it is evident that users make the choice of which sources to trust online based in part on their assessments of a source's credibility; users are judging credibility in complex and changing ways as the web becomes more social. In fields like HCI (human-computer interaction) and psychology, there has been an abundance of research addressing the question: What elements of websites contribute to trust?[13] Again, this research tends to speak in terms of the credibility assessment process, with the goal of identifying the features that tend to induce trust. Much of this work was driven by e-commerce in the early 2000s and the need for trust in online business transactions. At that time, the topic of trust in websites was of particular interest because online retailers were adapting to an environment in which there were no in-person salespeople or brick-and-mortar buildings to represent the company as in traditional commerce; instead, the website had to do the work of conveying the

[13] One complication is that there is a lack of agreement in the literature about terminology: Elements that contribute to trust have been variously referred to as trust-production methods, trust-inducing features, antecedents to trust, determinants of trust, trust cues, credibility mechanisms, and credibility markers, among other things. Despite the inconsistent terminology, they are all talking about the features of websites that signal credibility. For consistency in my analysis I refer to these as "credibility features."

company's values and credibility in order to persuade users to take the "leap of trust" of making a purchase, making an account, joining a mailing list, etc.

Despite the e-commerce emphasis of this body of research, the findings are still applicable to other types of websites, such as e-health sites. In any case, users must still trust the company to deliver a service or conduct a transaction via the internet, whether that involves a physical product or something more intangible like health information or support.

According to several synthesis studies of online trust (Bailey, Gurak, & Konstan, 2003; Beldad et al., 2010; Fogg, 2002; Wang & Emurian, 2005; Wathen & Burkell, 2002), two credibility features are visual appearance (e.g., images, color, page design) and usability (e.g., navigation, speed). Research suggests that trust assessment is an iterative process rather than a one-time judgment: Web users first look to the surface appearance of the website. If the website appears credible at first glance, the user moves on to a closer look at the information contained within the site (Wathen & Burkell, 2002). Information quality assessments might take into account credibility features that signal the depth, accuracy, currency, and usefulness of information. Other credibility features of websites include third-party guarantees such as seals of approval, privacy disclosures, brand or company reputation, and social presence cues (or a sense of connection to a real human or real offline organization) (Wang & Emurian, 2005).

Trust in online communities

Besides addressing the use of credibility features to establish trust between a customer and a company in e-commerce contexts, other research on online trust has taken the more social perspective described above and looked at how trust is established among peers in an online community. Many of these studies, particularly

those coming out of rhetoric, technical communication, and linguistics, have been analyses of user interaction in forums and other participatory spaces online, rather than empirical studies assessing user reactions or perceptions. Some studies focus more on strategies used by community members to project an overall credible ethos, while other studies may focus on broader rhetorical dynamics that affect trust at the community level. For instance, Boyd (2002), in his study of the eBay community, found that trust was built among peers based on factors such as adherence to community norms and language, the screen name and icons of other users, ratings of users' reputation and contributions, and familiarity with users built over time. Interestingly, he found that security features imposed from on high by eBay, such as insurance and escrow, actually damaged trust. These apparently paternalistic measures invalidated community trust by removing decision-making a step away from the community. Gurak (1997) likewise found that shared community norms, language, and values contributed to trust in an online protest.

Discourse and language analyses have investigated the language moves that authors use to convey credibility and authenticity in electronic discourse. Cheng (2008) found that students in an educational chat used the strategy of narrative. For instance, students used personal stories to build rapport or to display expertise. By studying the rhetorical failure of Nigerian scam letters, Gill (2013) identified aspects of electronic discourse that contribute to authenticity, such as tailoring content to the reader and demonstrating spontaneity (not "trying too hard" in a formulaic way; even typos could contribute to a sense of realness). He notes that authenticity is somewhat invisible: We tend to assume it of someone unless something stands out as fake. In online reviews, Mackiewicz (2010) found in the Epinions.com community that reviewers' credibility

strategies included assertions about one's expertise, familiarity with the product, or education, as well as indirect signals of expertise such as use of technical language. In addition, she found that the credibility of reviewers was established dialogically with other users; through the comment feature, others could verify or challenge a reviewer's expertise or sincerity. Several researchers (Graham, 2007; Morand & Ocker, 2003; Walther & Bunz, 2005) have pointed to the role of politeness and sociability in forming a functioning online community where trust can thrive.

Besides these moves of users to construct or invent their ethos in the Epinions community, Mackiewicz (2010) found that other facets of the website, such as ratings and join date, contributed to users' situated ethos. The reputation and recommendation systems, described above for their role in information credibility assessment, are becoming more common in virtual communities as well. These systems ascribe "more weight to the contributions of trustworthy people, [using] trust as a kind of filter. This way [strangers] can still make an estimation of the quality of the information and thus decide to proceed to trusting behavior" (Talboom & Pierson, 2013, p. 86); in spaces without metrics that indicate a poster's history and social rankings, aspects like profiles, photographs, and pseudonyms enable a user to build up a reputation (Whitty & Joinson, 2008).

Studies in other fields suggest how broader community dynamics and patterns of interaction, not just language and rhetorical strategies in individual users' contributions, promote trust in virtual community. For instance, disclosure of personal information, reciprocating disclosure, repeated interactions over time, and prompt and frequent responses created higher levels of trust within a community (Henderson & Gilding, 2004; Ridings, Gefen, & Arinze, 2002). Likewise, in the context of virtual work

teams, demonstration of trust placed in others (when time is too limited to develop a relationship) and timeliness and quality of responses have been shown to characterize high-trust teams (Jarvenpaa et al., 1998; Walther & Bunz, 2005). Conversely, Hughes et al. (2014) found that credibility can be diminished through attacks on users' expertise and trustworthiness in a discussion forum. Sillence (2010) found that, when assessing online advice, people tend to trust information that supports their pre-existing viewpoints.

So far, I have reviewed literature on trust generally and online, and I have addressed how Web 2.0, including user-generated content and social networking, has complicated it. As described in the section on e-health, the participatory web has been expanding into areas which have traditionally been considered the domain of experts, such as healthcare. As a result, the problem of trust in e-health has been a subject of ongoing concern. This literature review concludes, then, with a discussion of the trust issues unique to online health information.

Bringing it Together: E-Health and Trust

Much work on trust in e-health has addressed trust in terms of information credibility, for example, studies evaluating the objective accuracy of e-health information (Koerber & Still, 2008) or users' processes and criteria for evaluating its credibility. This focus of work was driven by concerns about users trusting inaccurate information online and experiencing harm. As early as 1995, medical professionals were formally meeting to address concerns with the credibility of health information on the web (Adams & Berg, 2004), and the topic remains important today. For instance, *Journal of Medical Internet Research* has a special e-collection on "Quality/credibility of

e-health and trust issues," with articles addressing credibility within diverse contexts such as medical e-books, YouTube, or mobile health applications.

The issue of trust and e-health information has received special interest for a number of reasons. According to researchers, many of these reasons mirror the challenges with online content generally, with some characteristics that make online medical information uniquely problematic:

- Medical information online often lacks authorship cues, which is especially important given the traditional emphasis on expertise and authority for medical information.
- The lack of official gatekeeping allows the proliferation of information that is outside of mainstream medical opinion (for instance, material on complementary and alternative medicine).
- Medical information quickly goes out of date.
- Informational and promotional content is often blurred. As an example, GlaxoSmithKline owns depression.com, a site that appears to offer objective information but that points users to the company's pharmaceutical products (Segal, 2009).
- Following online health advice can lead to harm. While it goes without saying that acting on medical misinformation can lead to real physical harm, Eysenbach (2008a) argues that even technically accurate medical information can be harmful if misapplied or taken out of context.
- People searching for health information online may already be experiencing anxiety that can become heightened by the search process

and access to the most catastrophic explanations for symptoms (Segal, 2009).

- People with a chronic, degenerative, or terminal illness may be especially vulnerable to claims about cures.

Problems and Solutions for E-Health and Trust

There have been several strands of research explored within the literature regarding e-health and trust. One strand of research has focused on assessing the accuracy of online health content (Kunst, Groot, Latthe, Latthe, & Khan, 2002; Thakurdesai, Kole, & Pareek, 2004; Walji et al., 2004; Zun, Blume, Lester, Simpson, & Downey, 2004). Some researchers have focused on evaluating the objectivity and thoroughness of medical journalism (Schwitzer, 2008). Not surprisingly, there is wide variation in the quality of health information to be found online. Another strand of research focused on how users assess the credibility of online health content. As found with generic credibility studies, users' assessments depend upon a variety of factors, though in some cases there has been special concern that users are swayed by the appearance and design of a health website rather than looking to the source (Eastin, 2001). Some work in the medical field has also examined the physical consequences of e-patients' following medical advice online (Crocco, Villasis-Keever, & Jadad, 2002). This research, though, has not turned up as many documented cases of harm as might be expected, given the media and scholarly concern about medical misinformation.

This work that has described problems with the quality of e-health information has grown into many proposed solutions. Several of these solutions have been based upon gatekeeping mechanisms, such as government health portals that guide users to approved websites (e.g., the NIH's Medline or healthfinder.gov), or even non-

institutional sites authored by doctors (e.g., Quackwatch.com). Another solution posed has been third-party quality evaluators such as the Health on the Net (HON) Foundation, a nonprofit organization based in Switzerland. This foundation certifies health websites on the basis of the HON Code – quality criteria such as authority, attribution, and transparency. Other work in computer science has attempted to develop automated measures to indicate trustworthy health websites (Wang & Liu, 2007).

Of course, such solutions are not comprehensive given the massive volume of health information online and the speed at which it changes. Additionally, some consider it unrealistic and even unethical to monitor health websites using universal criteria. These efforts fail to recognize the context-dependence and ambiguity of medical information, and could stifle the potential for users to take on more agency in their healthcare through e-health technology (Adams & Berg, 2004). Moreover, trustworthiness certifications generally only assess proxies of trust on a website and not necessarily the information itself, potentially giving users a false sense of security (Burkell, 2004).

Trust and Online Peer Support

A further limitation of the proposed solutions for e-health information quality is that most of the criteria proposed do not account for the situation of the patient-participatory web, even though, as discussed above, user-generated health content and medical social networking are becoming important resources for patients. In a literature review, Adams (2010) identified that, in light of Web 2.0, various disciplines have renewed concerns regarding reliability of health information.

For instance, scholars have identified concerns specific to the online medium for support groups. Earlier, I discussed the benefits of anonymity for enhancing disclosure in electronic support groups, but anonymity can also enable people to misrepresent themselves. As with any online environment, limited non-verbal cues can make it easier for people to engage in "optimal self-presentation" to outright deception regarding their identity and status as a patient (Wright & Bell, 2003, p. 50). Similarly, Demiris (2006) comments that the online environment can lead to "trolling" and impersonation. He notes that "the impact of deception can go beyond impacting the trust among members of the community and lead to a damaging effect on members' health care status" (p. 184). Feldman (2000), a medical doctor, defines the act of faking illness online as "Munchausen by internet" (p. 669), and he lists clues for detecting false identities in online medical support groups.

Other studies have measured the accuracy of claims in online support groups. One study found 6% of answers to questions in an epilepsy support group were inaccurate, and the researchers attributed this to the lack of medical professionals participating (Hoch, Norris, Lester, & Marcus, 1999). In another study of an unmoderated online group for breast cancer, researchers found only .22% of statements to be inaccurate or misleading, and most were corrected quickly. The researchers identified a group-based peer-review process operating in the community (Esquivel, Meric-Bernstam, & Bernstam, 2006).

So, given the possibility for deception and misinformation, how is trust formed in online support groups? First, several studies affirm the significant role of peer experience. A study comparing users' reactions to health information sites compared to discussion boards found that shared values and similarity are major contributors to

trust in a medical discussion forum, more so than traditional credibility markers such as information quality (Wang, Walther, Pingree, & Hawkins, 2008). Likewise, Moturu et al. (2008) state that experiential evidence from a peer may not meet information quality criteria such as objectivity or completeness, but that users find it useful. Sillence (2010) found that, in an online cancer support group, consumers (versus experts) “take a broader perspective on the nature of expertise as a trust factor, valuing lay expertise or experiential advice as well as medical expertise.” She noted that discussion forums offer perspectives that are "case based, usually vivid and perhaps more easily accessible than numerical information presented on more institutionalised sites” (p. 377). Other work has found that perceptions of source credibility in an online medical support group were positively correlated with similarity (the fact that others have “been through it”), intimacy, and quality of emotional support in an online group (Wright & Bell, 2003). Galegher, Sproull, & Kiesler (1998) explored how members of an online medical support group appealed to both scientific and experiential authority when giving advice, thus strengthening the community.

In the area of online medication reviews, Hughes and Cohen (2011) compared user reviews on Askapatient.com and CrazyMeds.com to professionally authored content. They found that users tended to provide accounts of day-to-day effects and rich descriptions, whereas professional content was more abstract. They conclude that “Current strategies for filtering online health searches to return only *trusted* or *approved* websites may inappropriately address the challenge to identify quality health sources on the Internet because such strategies unduly limit access to an entire complementary source for health information” (para. 5).

These studies suggest that personalization, social validation, and a supportive environment of similar individuals all play a role in the establishment of trust within online medical support groups.

Trust and Medical Privacy

Thus far, I have been discussing trust in terms of a user trusting information online, whether authored by medical professionals or peers. However, with users now openly sharing personal health narratives and medical data, an additional dimension of trust includes trusting that websites or peers will respect one's disclosure of personal health information. Laws like HIPAA protect patients' medical privacy in an institutional context, but do not extend to users voluntarily sharing their own information online. And even if companies and healthcare institutions are committed to protecting health data, the high value of health data makes such organizations more prone to attack by hackers and identity thieves.[14]

Medical privacy has been considered a particularly important kind of privacy, given the potential for discrimination by insurance companies or employers and medical identity theft, among other negative consequences of medical data disclosure. However, surveys have suggested that most people are open to the idea of disclosing medical data online, particularly if that disclosure is connected to an overarching purpose such as helping to speed the development of cures (Alston et al., 2012). Indeed, as mentioned above, transparent disclosure of a website's privacy policy can contribute to a site's sense of trustworthiness, but this need for trust with a user's medical data is heightened when the entire site is based upon user data.

[14] According to one estimate, on the black market, a medical record is ten times more valuable than a credit card number (Humer & Finkle, 2014).

Indeed, in the realm of e-health, there are important conversations happening about users' trust in medical information and the problems that can arise from greater disclosure and less gatekeeping of information. The question of trust, and how it is established rhetorically on e-health sites, will be addressed in the analysis chapters in this dissertation. The next chapter will first outline the methods used to conduct the analysis.

Chapter 3: Methods

Research Questions

The literature review has shown that trust in online medical information is complicated due to the potential for misinformation or exploitation. Even standard, information-based e-health sites raise questions about trust because of the newness of patient access to medical information without the physician as gatekeeper. But trust has proven especially complicated in contexts where patients themselves contribute to information. Therefore, my over-arching research question is: How does trust operate rhetorically in e-health sites? I am interested in the rhetorical features that work to establish trust in e-health websites as well as how trust operates rhetorically in the more interactive spaces of an e-health site. My three sub-questions, then, are:

1. How is trust established in three e-health sites' organizational information pages?
2. How is trust established in three e-health sites' medical information pages?
3. How is trust established among peers in an interactive patient forum on an e-health site?

Because my study is a rhetorical perspective on trust in e-health sites, my method is rhetorical analysis (put simply, the study of how persuasion operates). The first two research questions help me understand the rhetorical means by which e-health sites, at an organizational level, attempt to gain the trust of users, but in two different "levels" of an e-health site. The first analysis chapter addresses how trust is established at a more general level. Trust begins to be established before a user even accesses the information within a site – at the moment of their first impression of the website, the

organization behind it, and the organization's values. My first research question addresses the rhetorical features that contribute to trust in this context of organizational information pages.

Once a user has taken an initial step of trust in an organization, they may move on to access actual information about their condition.[15] The second analysis chapter, then, looks at the presentation of medical information within each site, which reveals more about the rhetorical features that contribute to trust in technical, specialized information. Specifically, the second research question investigates medical information pages about Parkinson's disease.

The third question helps me understand the special complications that arise in the most interactive spaces of an e-health website. Therefore, the third analysis chapter looks at interaction within one patient community hosted by WebMD.

In the remainder of this chapter, I describe my methods for answering the above questions. This includes addressing how I selected websites and how I analyzed them. I also reflect on ethical considerations and limitations of my study.

Data Collection Methods

Selection of Websites

E-health is vast, in terms of both the quantity and the variety of websites available to patients. As the literature review showed, there has been a shift from more passive consumption of information to more active participation online. I found it

[15] I do not mean to imply that an e-patient's approach to medical information is always linear like this. In fact, internet users typically access medical information pages through a search engine rather than by starting at a single e-health website (Fox & Duggan, 2013). However, many people still do approach it in this linear fashion, or even if they land on the information page first, may go back to investigate the website at a general level. Wathen and Burkell (2002) describe a typical user's credibility assessment process as an iterative one, involving a first visual impression followed by a closer look at content.

important to reflect some of this variety by conducting a comparative rhetorical analysis of three e-health sites that represent a continuum from more traditional (information-based) to more interactive. Therefore, for my first two questions I analyzed three different e-health sites: a governmental health information website (NIH.gov), a commercial health information site (WebMD.com or "WebMD"), and a commercial medical social networking site (PatientsLikeMe.com or "PLM").

Limiting my analysis to three websites enabled me to address each in some depth (versus a more superficial survey of a greater number of e-health sites). Yet, I did not limit my analysis to just one website (i.e., a case study) because I wanted my study to reflect the fact that no e-health site exists in a vacuum, but is one part of a much larger e-health landscape. As discussed in the literature review, it is typical for e-patients to consult information from a variety of sources.

On my continuum of informational to interactive, NIH.gov represents an informational site, because it is a primarily unidirectional website where users go for the main purpose of *consuming* medical information as published by the organizations, not for the main purpose of *contributing* to knowledge or interacting with the organizations or others. The NIH (National Institutes of Health) is the U.S. medical research agency and the largest source of medical research funding in the world. Its website, NIH.gov, serves as a source of information about the institutes' history, mission, and research agenda. The site also serves as a portal to governmental medical literature. Founded in the 1800s, the NIH has the longest history of the three organizations I analyzed. I was unable to determine when its website was founded, but it is at least as old as 1997 (the Internet Archive's oldest capture of NIH.gov is from that year).

WebMD, which came of age in the e-health boom of the early 2000s, reflects a hybrid site where informational and interactive features are blended. It is perhaps best known as a medical information site, publishing news and reference articles on a wide range of health topics. However, patients can also interact with information using the site's individualized tools, and with each other using communities for peer and expert support.

Meanwhile, medical social networking sites such as PLM are trying to turn the unidirectional model on its head, making users the main participants and, in a sense, the authors of information. Founded in 2004, PLM is the newest in my set of e-health sites and is the least conventional because it relies on the input of patient data to generate information about medical conditions and treatments. Users fill in a detailed profile in which they track relevant medical statistics and qualitative measures about their conditions (like a publicly posted electronic health record). Users are then able to search profiles to find "patients like them." PLM aggregates the data from individual user profiles into symptom, condition, and treatment reports for each condition. PLM's business model involves selling de-identified data to pharmaceutical companies for research; PLM itself engages in medical research and has even incorporated self-tracking devices into some studies. It also has a mobile app that makes it possible for users to chart their symptoms from anywhere. Another major service of the site is forums, providing patient-to-patient communication like WebMD's Communities. PLM is just one example of a company that is exploring the social dimensions of healthcare.

Especially when placing NIH.gov and PLM next to each other, it becomes clear that each type of e-health site has a very different relationship to its audience and very different purposes and features to reflect that. However, as the analysis will show, even

more information-based websites like NIH.gov are adopting interactive features, and interactive sites still present information. Therefore, “informational” and “interactive” are not meant to be strict categories but rather a continuum.

While I could have chosen from many other e-health sites such as MayoClinic.org, Yahoo Health, or CureTogether.org, I narrowed down my selection on the basis of the sites’ popularity. I wanted to select websites that best represent the public’s current understanding of e-health. WebMD and NIH.gov are the two most popular e-health sites, according to data from the Alexa Global Traffic Rank (“Top 15 most popular health websites,” 2014), with upwards of 150 million unique visitors per month for WebMD (WebMD Health Corp, 2014). In a Pew survey, of those users that had a favorite health site, WebMD was the top answer given (Fox & Rainie, 2002). NIH.gov and WebMD pages land among top hits for searches on common health topics like “obesity,” “Parkinson’s,” or “strep throat,” meaning that the average e-patient has likely encountered these sites. PLM receives much less traffic than the other two sites, but among medical social networking sites, it is considered by some to be the largest and best-known (Swan, 2009). It has seen major growth since its start in 2004, suggesting that it is catching more people’s attention and will continue to grow in popularity. According to its homepage, as of 2015, it has over 350,000 members representing over 2,500 conditions. The membership of the site and the number of conditions have more than doubled since 2012.

This sample of three websites allows me to comment on the range of strategies that e-health sites use to establish trust on their sites, but for my third research question I wanted to go deeper into how trust operates in a peer-to-peer space. Therefore, I analyzed a single patient community within WebMD. Again, because of

WebMD's familiarity, its communities may represent how the public understands online medical support groups.

Selection of Medical Condition

My analysis of e-health organizational information pages (Chapter 4) looks at the sites at a general level, but in order to complete my analysis of the medical information pages (Chapter 5) and patient community (Chapter 6), it was necessary to narrow the scope of my analysis to a particular condition. I selected Parkinson's disease. According to the Parkinson's Foundation (2015), it is a chronic, progressive, neurodegenerative movement disorder. Tremor, slowness, and rigidity are common symptoms. It affects slightly more men than women and tends to affect people 60 years and older.

Because approximately a million Americans have Parkinson's (Parkinson's Foundation, 2015), there is a good amount of information about it on the web. Parkinson's disease is a topic covered by each of the three websites, allowing me to compare each site's presentation of Parkinson's information. The condition is also represented among WebMD's Communities. I selected Parkinson's disease because it is a condition that is ongoing, complex, and affects daily life, so patients as well as caregivers are interested in learning more about it. In particular, because Parkinson's is incurable, affects people quite differently, can be difficult to diagnose, and has many (and controversial) treatment options, I reasoned that this disease would provide especially valuable insights regarding trust compared to more temporary or straightforward conditions.

Data Sources

One of the well-recognized challenges of rhetorically analyzing content from the web is that there are not always intuitive bounds to online content (Blythe, 2007; Gurak & Silker, 2002). Indeed, a researcher of the web can find themselves facing an infinite number of rabbit holes to explore for further analysis. Ultimately, my goal was to select webpages and discussion threads that represented the continuum of informational to interactive, that provided a wide range of information, and that constituted a large enough corpus to enable me to address my research questions. See Table 1 for a summary of what I studied. All three data categories are publicly accessible and require no login. I will describe my data selection process in more detail below.

Table 1: Data sources for rhetorical analysis

Research question	Data	Specific content used
1	Organizational information pages	Homepage, About page, employee profiles, and privacy policies of NIH.gov, WebMD, and PLM NIH.gov FAQs WebMD "What we do for users" page PLM Openness Philosophy
2	Medical information pages	PubMed Health (NIH) Parkinson's glossary and overview pages, research reviews abstracts page WebMD Parkinson's Health Center, Visual Guide to Parkinson's, and "Understanding Parkinson's" article PLM Parkinson's main condition page, Carbidopa-Levodopa treatment report, slowness symptom report
3	Discussion forum threads	About a year's worth of threads (107) in the WebMD Parkinson's Community from 2013-2014

Organizational information pages

My first research question was aimed at finding out the rhetorical means of establishing trust in an e-health site's organizational informational pages, or the organizationally- or corporately-authored pages where each organization establishes its

identity. Users will likely not engage with a site with much depth if they do not trust the motives of the organization or the reliability of the website, so the first impression a website conveys is key to online trust. These pages consist of the following:

- Homepage. As the typical gateway into a website, a company's homepage often constitutes a user's first impression of the company.
- About page. The About page is the company's opportunity to rhetorically construct its purpose, history and relationship to readers. It may also make explicit appeals to its character and credibility.
- Employee profiles. Descriptions of employees are valuable to examine because they represent the "face" of the company and an effort to present a more human side to the website. The information included about employees' credentials may also reflect company values.
- Privacy policy. Establishing trust on e-health websites is especially important because disclosing sensitive personal data on websites can involve risk for users. As norms for disclosing personal data change, it is interesting to examine organizations' rhetorical responses to (and attempts to shape) these changes, and the promises they make to users, in privacy policies.

All of the pages are accessible (entirely public and no more than a click or two away from the main page) and familiar (each is a common webpage "genre" that appears in all three websites for analysis). In addition to these four standard types of webpages, I chose to add to my dataset some additional webpages which helped to define the organization's identity and which were easily accessible: the NIH's FAQs (frequently asked questions) page, WebMD's "What we do for our users" page, which is

linked from the About page, and PLM's "Openness Philosophy," a prominently-promoted counterpart to its privacy policy.

Medical information pages

Once someone has decided an organization seems trustworthy, they may look deeper in the site for medical information. Medical information about a condition represents a more specific level at which e-health organizations attempt to create trust. For the second analysis, then, I studied each website's medical information pages about Parkinson's disease. I aimed to find articles from each website that would be a logical starting point for someone researching the condition. Therefore, in narrowing down which pages to include for my analysis, I selected those that were especially prominent and accessible,[16] and that seemed to serve a similar function as an overview or informational page.

On WebMD and PLM, the Parkinson's information pages were easily identifiable – there is a single Parkinson's Health Center on WebMD and a single Parkinson's condition page on PLM. Within NIH.gov, however, there were several options. Many different institutes of the NIH have developed their own informational pages about Parkinson's. I chose the PubMed Health pages because they were near the top of search results for Parkinson's and because the PubMed Health database names consumers as one of its audiences.

[16] Each website's medical information is fully public, although on PLM, members of the site who are logged in have access to all patient profiles from the condition pages. I analyzed the PLM pages while not logged in, to mimic a user just browsing the site and to protect confidentiality of members who have chosen not to display their profiles entirely publicly. About 10% of members choose to make their profiles accessible to non-members. For more about measures I took to protect patient confidentiality, see "Ethical Considerations" below.

It was also important for my data collection process to account for the fact that users likely do not limit themselves to one single page: The main Parkinson's information pages for each website were all heavily hyperlinked and it would be natural for an e-patient to explore multiple links within them. Therefore, for each website, I expanded from the single main Parkinson's pages to pages no more than a click or two away. For example, for the PLM Parkinson's condition page analysis, I also analyzed the reports for slowness (the first listed symptom) and Carbidopa-Levodopa (the first listed treatment). The specific pages analyzed on each website are found in Table 1 above.

Forum interaction

While my first two analyses focused on the organizations' rhetorical means of inducing trust, discussion forums provide insight into how *users* build trust in the context of community. Discussion forums, places where peers communicate and exchange information, are a common object of study in internet studies, educational research, and psychology, among other fields. They are especially valuable for understanding trust in patient-participatory websites because they represent one of the most interactive aspects of an e-health site.

On WebMD, it is the WebMD Communities that make the website stand out as more than just an informational site. I selected threads from the WebMD Parkinson's Community. Within the forum, I could have selected threads based on which were most active or that resulted from a focused search on a particular topic in the forum, but my goal was to get a thorough picture of typical forum interaction. Therefore, I analyzed a "time slice" representing about a year's worth of threads. There were 107 threads (consisting of a total of 409 individual comments) that had been last updated in

approximately 2013-2014. Posts are not dated by the actual date, but by how long ago they were posted, e.g., “1 day ago,” “3 weeks ago,” or “2 years ago.” This makes it difficult to identify a specific date range for the postings.

I selected the rough timeframe based on a few criteria. I could have gone back to the earliest posts that were accessible (approximately 2006), but it is likely that group members had not yet formed community norms at that time, making these posts less rich for analysis. I could have chosen only the most recent posts, but then I would run the risk of missing ongoing conversation. Choosing posts from only one to two years ago allowed me to capture the activity of a mature community. At the same time, most of the conversations from a year ago had run their course, allowing me to study more complete threads.

Capturing, Managing, and Storing Data

Another challenge of internet research is that websites are unstable, and as a result researchers must find ways to capture their own copies of webpages (Blythe, 2007). In fact, the PLM homepage was redesigned at least twice since I first started browsing it in 2012, and WebMD underwent a design change during the time period I was analyzing it. Besides the overall layout of a site, news articles and updates may change daily.

My main tool for capturing and organizing webpages and discussion threads was Zotero, an open-source reference management system. Zotero takes “snapshots” of webpages, or stores an image of a webpage on a particular date. This is much like taking a screenshot or saving a .pdf of the page, but also retains some of the interactivity by enabling links. However, Zotero snapshots do not retain the exact design elements of the original page, so I also saved the URL to each page to refer to

during the analysis, while comparing back to the snapshots to be sure that the page did not change significantly enough to affect my analysis. I also saved screenshots of relevant aspects of webpages. This combination of visiting the actual website and saving screenshots and Zotero snapshots enabled me to keep as close of a record as possible of both the look and the interactivity of a page at a given time.

For consistency, I aimed to analyze versions of webpages that were saved during a similar period in time. For instance, the NIH.gov, WebMD, and PLM organizational information pages were all captured in the same month in 2014. The NIH.gov and WebMD medical information pages were captured in 2015, several months after the PLM condition pages, but the only thing that had changed on PLM in the meantime was the numerical information for the data displays. I was able to store the URLs and all related files in Zotero folders designated for each website and analysis.

To organize the discussion forum data, in addition to saving snapshots of the pages in the discussion forum to capture them in their original context, I copy/pasted the threads into Word documents where I could highlight and comment as I analyzed. I also kept track of all threads I was using in a master spreadsheet where I assigned a thread number, the date the thread was started, the original poster's screen name, that poster's code name (see "Ethical Considerations" below for more), whether or not it was designated as containing expert content, the number of replies, the subject line, the full text of the original post, the topic, and a summary. See Figure 1 for an example (invented to protect privacy).

Thread Numb	Screenname	Expert?	# repli	Thread title	Text of OP	Thread topic	Summary
16	MJF_fan	y	4	Anyone tried DBS?	I'm going in for a consult next week. Just wanting to hear others' experiences to help me decide whether I want to go through with it.	Question about treatment	Someone posts a question about DBS; others chime in with their experiences. The experiences are mixed so some debate ensues about whether it is a worthwhile procedure and what the limitations are.

Figure 1: Example entry for discussion thread spreadsheet

I reproduced quotations verbatim except for pseudonyms (e.g., Dr. Jones, or initials to distinguish posters in an exchange), places where I omitted content for length (indicated by ellipsis), and places where I removed location or potentially identifying information (indicated by brackets). Retaining all typographical errors and abbreviations provided a truer picture of the informality that characterizes group interaction.

Content stored in Zotero was synced to my password-protected account on Zotero.org. In addition, all data was saved on my own password-protected computer and backed up periodically to an external hard drive.

Analytical Methods

Rhetorical Analysis

Because I am interested in trust and how it is established rhetorically, I have chosen the tools of rhetorical analysis as my method. Also known as rhetorical criticism, rhetorical analysis is a well-established method within the field of rhetoric and technical communication. According to Gurak and Silker (2002), "One need only casually peruse the technical communication journals to find numerous examples of the use of rhetorical analysis as a research method in the discipline. Rhetoric has played a major role in the development of technical and professional communication theory and practice" (p. 235).

Rhetorical analysis involves applying elements of rhetorical theory to understand how persuasion, argumentation, and communication operate in texts, with "texts"

construed broadly to include visual and multimodal elements. It closely examines "word choice, arguments, warrants, claims, motives, and other purposeful, persuasive features of language, visuals, and various artifacts" (Lay, Gurak, Gravon, & Myntti, 2000, p. 7). While it was traditionally often used to study public speeches, it is now used to study a much wider range of texts including communication in digital contexts (Gurak, 1997; Logie, 2006; Reyman, 2010) and in medical contexts (Lay, 2000; Segal, 2005; Stone, 1997).

The flexibility of rhetorical analysis makes it an especially suitable method for study of websites: It enables me to consider the rhetorical role of non-textual features on the site, such as visuals, video, and even navigational features built into the site. Warnick (2005) argues that digital texts, with their personalization, interactivity, and complex authorship, require broader critical approaches than typical "print-centric" criticism.

Rhetorical analysis is subjective yet empirical: It is based upon real evidence and observation yet "retains the critical and somewhat broad lens of a narrative or literary critic" (Gurak, 1997, p. 5). It involves the in-depth study of the "rhetorical dynamics"[17] within specific contexts, thereby helping to illustrate the nuance within overarching theories and understandings of rhetoric and writing. In my case, I am applying the idea of trust, not traditionally addressed in rhetoric except through the narrower concept of ethos. Trust, ethos, and credibility are closely linked but

[17] I borrow this term from Gurak (1997), who used it to describe some of the broader elements that contribute to persuasion in an online community. While the term "credibility features" is helpful for describing contributors to trust on webpages, the term "rhetorical dynamics" seems better able to account for contributors to trust that develop over the course of time or repeated interactions. As such, it figures most prominently in Chapter 6, the analysis of an online patient community.

broadening out to trust can provide more robust perspectives on rhetorical dynamics in interactive spaces.

I consider the first two analyses to be comparative rhetorical analyses, because I am interested in how rhetorical features compare or contrast from informational to interactive e-health sites. While not all comparative analyses label themselves as such, it is a common practice to analyze texts (such as websites) side by side in order to make better claims about the range of variation of rhetorical features. For instance, both Brock (2012) and Spoel (2008) compared multiple websites in terms of how each presented its ethos.

Analysis Process

For all three analysis chapters, my overall approach was similar. I first read through all data sources in an open-ended way, to get, as Bazerman (2008) says, "a more grounded sense of what they are like and say" (p. 331). I drafted open-ended descriptions of the data sources. In later phases, I approached the data in more focused ways, searching for patterns and focal points. My process was inductive – generating themes and categories from the data itself rather than from a predetermined framework – but it was informed by previous literature on trust, ethos, and credibility. This meant that I used previous understandings of how trust operates in websites and online communities as a starting point for analyzing my data, but that I was open to additional themes and questions emerging as I progressed in the analysis. As discussed in the literature review, existing taxonomies and frameworks for online trust may not take into account the ways trust is established in more interactive and participatory spaces, so I found it important to be open to especially interesting or surprising aspects of my data. Though I followed this general process for each analysis,

I adjusted my approach and framework for each one because the data for each analysis chapter was different.

Analysis process for research question 1

When analyzing the organizational information pages for research question 1, I read through each webpage to identify words, arguments, images, videos, or page design features that signaled the character and credibility of the organization. Previous work in fields such as computer science helped attune me to features that have been found to contribute to trust in websites, such as third-party guarantees and social presence cues. I approached the webpages in an open way to inductively generate categories of credibility features on the websites that contribute to a site's ethos, for example, design, affiliations, references to people, and use of visuals and video.

Analysis process for research question 2

When analyzing the condition pages for research question 2, I brought work on visual rhetoric to the data to help me account for the visual presentations of medical information. I also incorporated perspectives on information credibility since my focus here was on information more than on the company or users. This literature attuned me to features that signaled the accuracy, objectivity, currency, etc. of the information. I identified categories of credibility features such as writing style, use of citation, usability, and use of visuals.

Analysis process for research question 3

The analysis for research question 3 focused on interaction in an online patient community. This analysis was focused on primarily textual data, but a greater quantity of data, making this analysis process somewhat more complex than the previous two. I looked for individual words, phrases, or arguments in the postings that connected to

my understanding of online trust from previous literature, and used those to help me develop categories and themes. For example, because anonymity and identity are important factors shaping online trust, I identified the role of signatures to be important and paid attention to it throughout the threads. In addition, as the role of community emerged as central to trust-building, I went back to keep track of places where forum members talked about their community or trustworthy and untrustworthy individuals.

This analysis of the discussion forum took place in multiple phases. In a first pass through the discussion forum data, I focused on original posts[18] to determine the topic for each thread. I also looked for strategies posters used to position themselves and convey the legitimacy and sincerity of their questions. Several of the threads had only a few responses (or none at all), suggesting a somewhat low level of interaction, or at least a limited exchange in which a question could be answered relatively straightforwardly.

In later passes through the discussion forum threads, I examined threads in their entirety to capture more interactive rhetorical dynamics that contributed to trust, such as affirmations of others' input or the development of relationship over the course of a thread. One challenge of using discussion threads as data is that I have no way of knowing for certain whether or why posts or posters were trusted. So, I identified less-direct indicators of trust (e.g., expressing intention to take another's advice or engaging in increasingly deep levels of self-disclosure). Then, based on what previous research suggests about trust in online communities, I made educated guesses about the rhetorical dynamics that may have contributed to trust. This approach led me to identify

[18] By "original post" I mean the first post that begins a thread. The "original poster" is the person who started a thread.

categories such as a polite and supportive tone, identity and identification, and experiential knowledge as factors that contributed to trust in the community.

Ethical Considerations

Given the unclear distinctions between public and private information on the internet, one of the major challenges for digital researchers is how to engage in research ethically, and when and from whom to seek permissions. Gurak and Silker (2002) say that one of the first steps in understanding how to handle online content is to determine whether the posts constitute published texts or written versions of oral conversations. Since my goal was to rhetorically analyze webpages and asynchronous forum postings, rather than analyze real-time user interactions through a method such as ethnography, I consider my data to be texts, rather than written versions of conversations. Therefore, I first applied for exempt status with the IRB (Institutional Review Board). The IRB subsequently required me to submit an application for expedited review. Breuch, Olson, and Frantz (2002) suggest that researchers think of the IRB application process as an opportunity to reflect on the ethics of a study; indeed, working with the IRB provided accountability and an opportunity to think carefully about protections for those whose comments I was analyzing.

In my case, I found that, because of the nature of internet research, additional or adapted steps were required in order to work with the IRB successfully. I worked closely with the IRB, especially regarding the use of patient postings as data for the third analysis chapter. Based on their review of website policies, I chose to analyze the WebMD patient forums. The IRB approved[19] my use because of my thorough plan to

[19] University of Minnesota IRB study number: 1405P50561.

address risk and confidentiality issues as well as because the postings were fully publicly accessible with no login required. Part of what made for a successful IRB review process was, I believe, providing lots of detail about the scope of my study and the ways in which it differed from traditional human subjects research. Providing this additional detail was challenging; I noticed as I was completing the forms that I could not simply check "yes" or "no" in answer to questions on the form. Rhetorical analysis of online texts, and indeed much internet research, can be difficult to define in IRB or "human subjects" terms, which were originally set up for biomedical research.

On the IRB form, for situations where my study did not "fit" the expected format, I included appendices explaining why I did not answer a particular question or providing samples of data to help illustrate my approach. As an example of one of the complications I faced, the IRB asks for demographic information about participants and the process for recruitment and consent. I had to explain that, because I am not studying the participants themselves, but rather their *language* in the forums, to seek consent or collect demographic data would actually compromise privacy, as it would require me to collect more identifying data than I need (such as e-mail addresses). Furthermore, certain users may not be accessible or active on the forums anymore (especially since I used some discussion threads which were up to two years old).

Even though my study did not involve the typical steps of recruitment and consent, I nonetheless needed to spell out how I would protect confidentiality, which was the major ethical consideration for my study. Rhetorical analysis of online texts does not require me to interact with actual human subjects, but the texts I use as data have nonetheless been composed by humans. The internet provides access to conversations that would not have otherwise been available, and it is important to

remember that many participants in these online conversations have a perhaps misguided expectation of privacy online or of what the risks of disclosure online are.

The AoIR (Association of Internet Researchers) has published some ethical guidelines for online research; a general principle is that "the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality, right to informed consent, etc." (Ess & AoIR Ethics Working Committee, 2002, p. 5). In addition, individuals may not expect their statements to be republished out of their original context, such as a research study. As an example of one study that considered such questions, during Gurak's (1997) research of online protests, she recognized that users posted to forums with the full knowledge that their post would be public, but that they likely expected that their postings would only be viewed in that context, which led her to use pseudonyms. Gurak predicted that as the internet continues to expand, this expectation of privacy would decrease.

I chose only fully public webpages for research questions 1 and 2. For research question 3, I chose the WebMD Communities to study because they are fully public and accessible without a login (some user-created communities on WebMD can be set to be more private; I did not analyze those). Even though the discussion forums are public, it is possible that some users expect greater privacy in the forums than they truly have, or that they do not expect their words to be reprinted out of the context of the forums. And, I felt an even greater responsibility to protect users' confidentiality because of the sensitive, traditionally private nature of medical information. While online support groups are not new, norms and expectations about disclosure may not yet be established in every context.

Indeed, any participant in an online forum takes on risk when they post medical information that could be linked back to their identity, but users of WebMD have decided that the benefits of using the site exceed the risks. I explained to the IRB that the risks of my study would be less than any pre-existing privacy risks that users take on when using the site, because of the extra steps I would take to de-identify data. And, the audience of the forum postings in their original context – where thousands of people may have already viewed them – is much larger than the audience for my study.

The major steps I took to protect confidentiality, as described in my IRB protocol, were 1) using codes (initials not connected to screen names) instead of screen names, even though many screen names are already non-identifying, 2) blocking out any personal photographs[20] or screen names in screenshots used in this dissertation, and 3) deleting identifying information in comments. The flexibility of rhetorical analysis, which looks for patterns and repeated moves in texts, enabled me to take some liberty with how I represented content from the discussion forums. For instance, I could choose to quote, summarize, or aggregate (e.g., list) small segments of text from the forums, rather than quote posts in their entirety (I also did not indicate thread titles), thereby avoiding sensitive personal information and making posts less traceable to their authors.

Limitations

My study is limited in that I only analyzed three websites. I intended for each website to serve as an example of a different type of e-health site, but my small sample

[20] For screenshots, I avoided images of people I thought were real patients even on public pages; stock photos or images of public people (e.g., NIH director Francis Collins) I left in.

excludes other types of e-health sites such as those by medical institutions (e.g., Mayo Clinic).

A limitation of my discussion forum analysis is that the WebMD Parkinson's Community is not as active as some other online communities. The scattered nature of postings, and the large number of one-time posters, means that members may not have as many opportunities to build trust over time. Several original posts received no response, and even in cases where the original poster received advice, the original poster often did not come back to follow up or comment on the response, limiting my ability to judge whether particular posts were trusted or not. My method cannot explain why posters fail to come back or why threads "die." Perhaps the original poster is satisfied with the response, does not have time to follow up, or disagrees with or distrusts the advice.

Other online communities, where engagement is more sustained and where there is a larger group of regular posters, may better represent a community where trust is operating successfully. For example, the Parkinson's community on PLM is much more active, possibly because there is a greater feeling of safety due to the seemingly less public nature of their postings, as they require a login to access.[21] In addition, PLM's integration of the discussion forums with the detailed profiles may enable users to gain a fuller picture of their fellow forum members. A valuable future research project would examine how trust is built in communities that offer more and less anonymity, and more and less privacy. In addition, in more active forums, it is likelier that members

[21] Unfortunately, I was unable to study the PLM forums. I sought approval from the company to use discussion forum data, but they need to be considered a collaborator on external research and do not have resources to review and participate in all study requests.

would speak specifically about trust, privacy, and community issues. Moments where members are having conversations about these matters would yield valuable insights into how people trust each other, including newcomers and longtime members.

In addition, although the WebMD Communities are large and easily accessible, they are not typical in that they contain an expert moderator,[22] limiting my ability to generalize to other online support groups. A study of an unmoderated group would provide an interesting comparison in terms of attitudes towards physician authority. Still, there was a moment in the time slice I analyzed where the moderator dropped out, providing me with some insight into how the forum operated with and without expert oversight.

Others have studied discussion forums using ethnographic methods, acting as a participant observer. This approach may help to better understand what the experience of participation is like for users. However, because my focus was on communication and rhetorical dynamics, not on the participants themselves, I did not find it necessary to post in the forum myself or contact users. By not interfering in the forums, I could be sure that their communication had not been influenced by knowledge of a researcher. Moreover, the interference of a researcher into a forum focused on a medical issue may be distracting to users.

It is also important to acknowledge what the method of rhetorical analysis *cannot* tell me. Brock, Scott, and Chesebro (1989) write, "Of course, critics have no direct access to the inner motivations of others… Literary critics use the term *intentional fallacy* to capture the host of issues that emerge whenever one claims to

[22] Wang, Walther, Pingree and Hawkins (2008) observe that few healthcare providers participate in online support groups.

identify and understand all that motivates others" (p. 12). By focusing on websites and texts as my data, I cannot make claims about the organizations' or users' motives in using certain strategies or language; likewise, I cannot make claims about the *effect* of such strategies. Though I am unable to determine intention through analysis of texts, Mackiewicz (2009) observes that writers and audiences convey and assess credibility "whether consciously or unconsciously" (p. 5); in other words, persuasion and trust may operate at an unconscious level that would make it impossible to determine writers' and users' intentions or perceptions, even if I did ask them directly about it. Nevertheless, other methods, such as interviewing, usability testing, or surveying, would have provided better insights regarding motive and effect, and would provide a valuable perspective to complement this rhetorical analysis in the future.

Brock, Scott, and Chesebro (1989) continue, "We hold criticism to be an art of evaluating with knowledge and propriety…it not only posits a judgment, the judgment is explained, reasons are given for the judgment, and known information is marshaled to support the reasons for the judgment" (p. 13). In other words, despite the interpretive and subjective nature of rhetorical analysis, it is still grounded and based in data and in previous knowledge, and in my case that previous knowledge is research in multiple disciplines and using multiple methods (e.g., experiments measuring user reactions to website features). As indicated by many of these other studies and their varied findings, trust is influenced by many context-dependent factors. Therefore, the goal of rhetorical analysis, which is interpretation rather than generalization, is especially appropriate for understanding in an in-depth way how rhetorical concepts operate in a limited number of texts.

In conclusion, though my study has limitations, a rhetorical analysis is still a valuable approach to understanding a phenomenon such as trust on e-health sites. I cannot generalize much from my small sample, but the goal of my study is not to generalize but to provide a rich, contextualized perspective on how trust operates. This perspective can still be used to shed light on similar situations and contribute to theory-building over time. Now that I have laid out the methods used to conduct the analysis, the proceeding three analysis chapters will detail the results.

Chapter 4: Ethos in E-health Sites' Organizational Information Pages

Medical information has been accessible on the internet for years, and looking up conditions and symptoms has become a common practice. Today, a wide variety of e-health sites are available to patients, from traditional information-based forms to more social, interaction-based forms. Regardless of whether a website is more familiar or more novel, it must establish trust in its website and its organization in order to be successful. A user's first encounter with an e-health site is an important one. Based on the public face an organization projects, a user may determine whether they wish to engage with the site further as a source for information.

Therefore, in this chapter, I look at the organizational information pages[23] – the first thing a user sees – to see how e-health organizations attempt to gain the trust of users through rhetorical means, chiefly the construction of a credible ethos. I analyze how each website constructs its ethos via textual, visual, and interactive features that signal credibility.[24] Based on the type of website, those individual credibility features, and the overall ethos a site projects, may differ importantly. Therefore, this chapter compares three popular e-health sites – NIH.gov, WebMD, and PatientsLikeMe.com – to paint a broader picture of the e-health landscape and how e-health sites attempt to inspire trust.

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[23] As explained in Chapter 3, the best places for seeing how organizations establish ethos are home pages and other each-to-access pages like the About page, employee profiles, and privacy policy. This analysis looks at comparable pages across the three websites.

[24] As explained in Chapter 2, I take *ethos* to mean a rhetor's projection of their character and credibility. Therefore, I see it as linked to the rhetor's identity. I use the term *credibility*, however, to refer to qualities like expertise, accuracy or sincerity, that can characterize the disparate elements that contribute to a rhetor's overall ethos.

NIH.gov and WebMD already have credible reputations for a number of reasons, including their histories and significant funding sources.[25] The sites have also rhetorically shaped the content and design of their sites to project credibility, as would be expected of any major organization with a multi-million dollar budget, a portion of which certainly goes to web design, promotion, and copywriting. PLM is lesser known and therefore may need to do more work to construct a credible ethos, but it is still a commercial website with the resources to invest into its public presentation.

As illustrated in the remainder of this chapter, all three e-health organizations project a successful ethos.[26] However, each does so in a different way. NIH.gov relies primarily upon *expertise*-based credibility features, projecting an ethos of governmental and scientific authority. WebMD likewise relies upon expertise, in addition to patient-centered features, to project a professional yet personal ethos. PLM uses some reference to expertise, but mainly signals credibility via social and community-based features, thereby projecting a communal, participatory ethos.

NIH.gov's Organizational Information Pages

The NIH.gov website (see Figure 2) makes its governmental identity clear. The name and logo of the U.S. Department of Health & Human Services can be found in the upper left corner of the NIH homepage. Below that is the larger NIH logo with its full name, "National Institutes of Health," and its slogan, "Turning discovery into health."

[25] The NIH is funded by the government; WebMD is funded by advertising.

[26] Not to everyone, and not entirely. But each site is quite popular, likely due in part to the careful work they have done to signal their credibility.

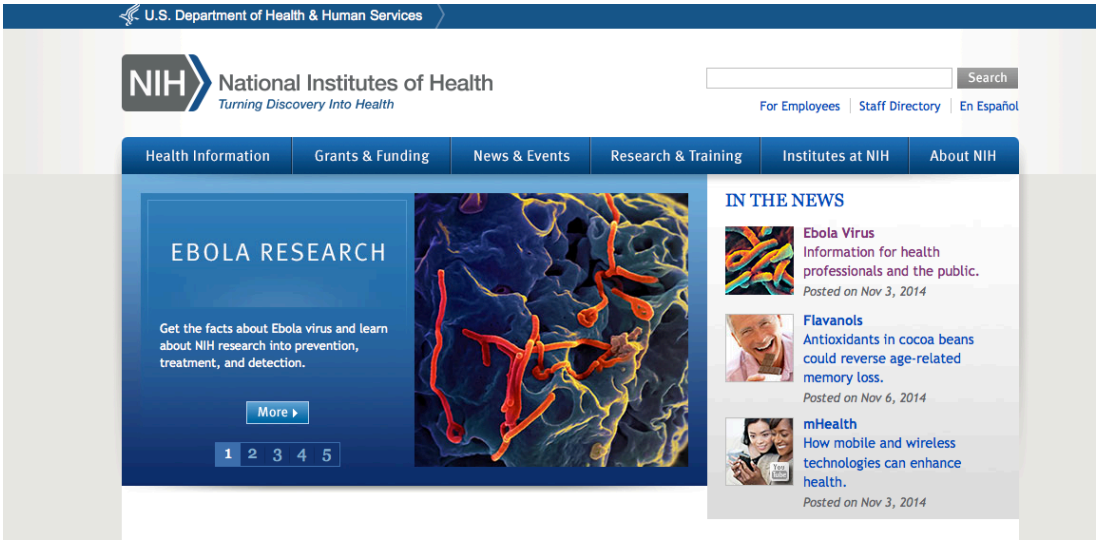


Figure 2: NIH.gov homepage, part 1

The website's information is organized according to the menu across the top, which consists of five drop-down categories: Health Information, Grants & Funding, News & Events, Research & Training, Institutes at NIH, and About NIH. These categories tell a quick story about the purpose of the organization and what it can provide for users, which is primarily information about the institutes and its research.

The webpage has both textual and visual elements, with the focal point of the page a revolving slideshow of featured articles against a dark blue box. To the right of the box are three recent "in the news" articles, showing that the site stays up-to-date. The focus on Ebola is also understandable because of the timing (Fall 2014). During the Ebola outbreak in West Africa, with some isolated cases in the United States, many were looking to the government for information about how government agencies would fund research to cure Ebola, enforce quarantines to keep the disease contained, or control the disease were it to spread in the United States. The subtitle "Get the facts about Ebola…" suggests that the NIH sees itself as an official source of facts at a time when it was easy to be misinformed by rumor and speculation.

Scrolling down, another box is visible, providing more information about the NIH. It is divided into tabs such as NIH at a Glance, Labs at NIH, and Training at NIH (see Figure 3). The NIH at a Glance information is placed above an aerial photograph of the NIH campus in Bethesda, Maryland, showing that the NIH is a real, physical location. The presence of the Visitor Information link also signal credibility by making it clear that this is a real place.[27]

Figure 3: NIH.gov homepage, part 2

To the right is a photo of the NIH director, Francis Collins. Showing a human being behind the organization further increases its credibility. He is referred to as Dr. Francis S. Collins, drawing attention to his expertise as a doctor. Next to his picture, icons indicate other ways to stay updated (Twitter, his blog, etc.) which present him as a somewhat accessible and open person. There is also a separate page dedicated to information about Collins, which is linked to several times from the homepage and About page. There, he is described as "a physician-geneticist noted for his landmark discoveries of disease genes and his leadership of the international Human Genome Project," and his various awards and memberships are listed. This is unsurprising

[27] Social presence cues that signal a connection to a real person or organization have been found to be important credibility features of websites (Wang & Emurian, 2005).

information to include in a NIH director biography – his discoveries and credentials align with the NIH's research mission.

Further down the homepage are more links to information pages within the NIH website, each with an associated image, such as a stock photograph of a person or a medical image such as a brain scan. Additional scientific imagery such as the Ebola virus, lab equipment such as microscopes, and photographs of scientists at work all signal scientific expertise to build the organization's credibility. Meanwhile, word choices on the homepage suggest how users are to engage with the site. For instance, verbs on the site suggest that users' actions include learning and finding: "Learn about a new Presidential focus aimed at revolutionizing our understanding of the human brain," "Learn how…," "Find information," "Find resources," etc. These headings are in line with the site's purpose as informational – there is no place for users to log in to engage with the site in a more interactive way or to post content of their own.

The scientific theme is carried through in the text of the About page, which relies heavily on statistics and facts to make a case for the credibility of the NIH. For instance, it reads, "Life expectancy in the United States has jumped from 47 years in 1900 to 78 years as reported in 2009," and "More than 80% of the NIH's budget goes to more than 300,000 research personnel at over 2,500 universities and research institutions. In addition, about 6,000 scientists work in NIH's own Intramural Research laboratories." The About page describes several of the NIH's offices and institutes. The page includes a section on history, and notes that 145 Nobel Prize winners have received support from the NIH. The About page also explains that "Successful biomedical research depends on the talent and dedication of the scientific workforce." The NIH also depends on public involvement, such as volunteers for clinical trials. The central

message conveyed is that the NIH exists for the benefit of the public and that the NIH has played a historical role in supporting health and medical advances.

NIH.gov includes an easy-to-find privacy notice, which opens with “Protecting your privacy is very important to us.” On the right side of the page are links to each section of the policy, making it easy to see the contents at once. The privacy policy is reasonably specific, even summarizing how NIH.gov uses third-party sites such as social media sites (and even links to these third-party privacy policies). This privacy policy holds to a standard view of privacy as valuable. Because it is specific and relatively transparent, it helps convey a sense of sincerity and goodwill towards users, further building up the credibility of the NIH as an organization.

The website, however, does not seem designed with the everyday user in mind. While there are no broken links, the organization is not especially intuitive and it is not clear exactly who the site and the information is for: At various points the articles refer to providing information for “health professionals,” “the public,” “employees,” “parents,” and “caregivers.” In other words, patients or users are not central. Instead, there is an emphasis on the NIH serving as a source of official guidelines and facts. This official, authoritative ethos is shown in the NIH’s definition of itself: “*The* nation’s medical research agency” (emphasis mine).

Another indicator of this official ethos appears in the FAQs section, which addresses questions not just about the NIH but about more general health issues such as, “Can NIH offer any advice when searching for health information on the Internet?” or “Where can I find information about alternative medicine?” This suggests that the NIH is seen as a trusted organization that can serve as a source for common health questions,

as well as advise e-patients on how to navigate other, potentially less credible, health information sources online.

The NIH has signaled its credibility in powerful ways by highlighting its link to a real physical location with a history, the expertise of its employees, and its quantifiable scientific and health impact. Scientific imagery, a largely non-interactive information design, and official rather than user-centered language contribute to the NIH's ethos of scientific rigor and official government authority, and highlight its central purpose as providing information. Such features are important in showing how the NIH stands out in an age where misinformation can flourish online. While the NIH website offers little room for user participation, WebMD demonstrates a blend of both informational and interactive purposes.

WebMD's Organizational Information Pages

An analysis of WebMD, which is a commercial site and has moved in a more participatory direction than NIH.gov, offers some interesting contrasts to NIH.gov. WebMD's very name shows the main source of its credibility: medical expertise. However, it is clear that WebMD is a commercial website, with its .com domain name and banner ads along the top and sides. In the top left of the homepage (see Figure 4) is the WebMD logo, followed by a search box with the option for focused searches for symptoms, doctors, or health care reform topics. Sign-in and social media links can be found to the right. Like the NIH website, the site's major categories are listed across the top as drop-down menus: Health A-Z, Drugs & Supplements, Living Healthy, Family & Pregnancy, and News & Experts. While the NIH's categories refer more to organization-specific information, these categories are user-focused, leading users directly to health

topics they may be interested in. These basic page elements remained consistent from an earlier version of their website (see Figure 5).

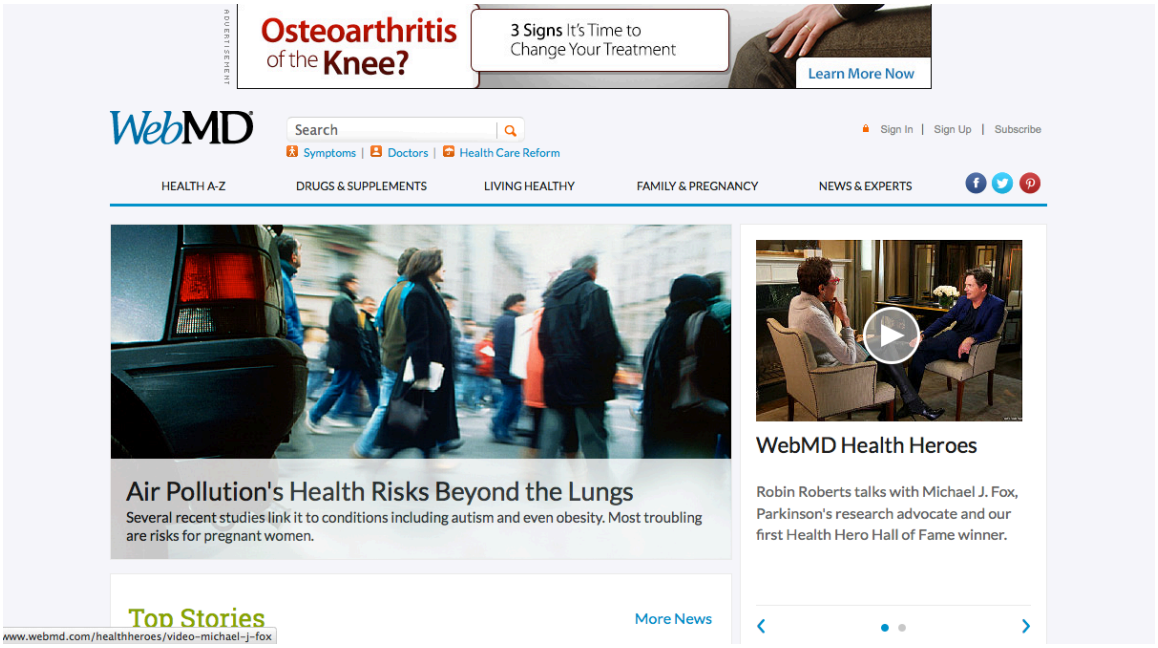


Figure 4: WebMD homepage (Fall 2014)

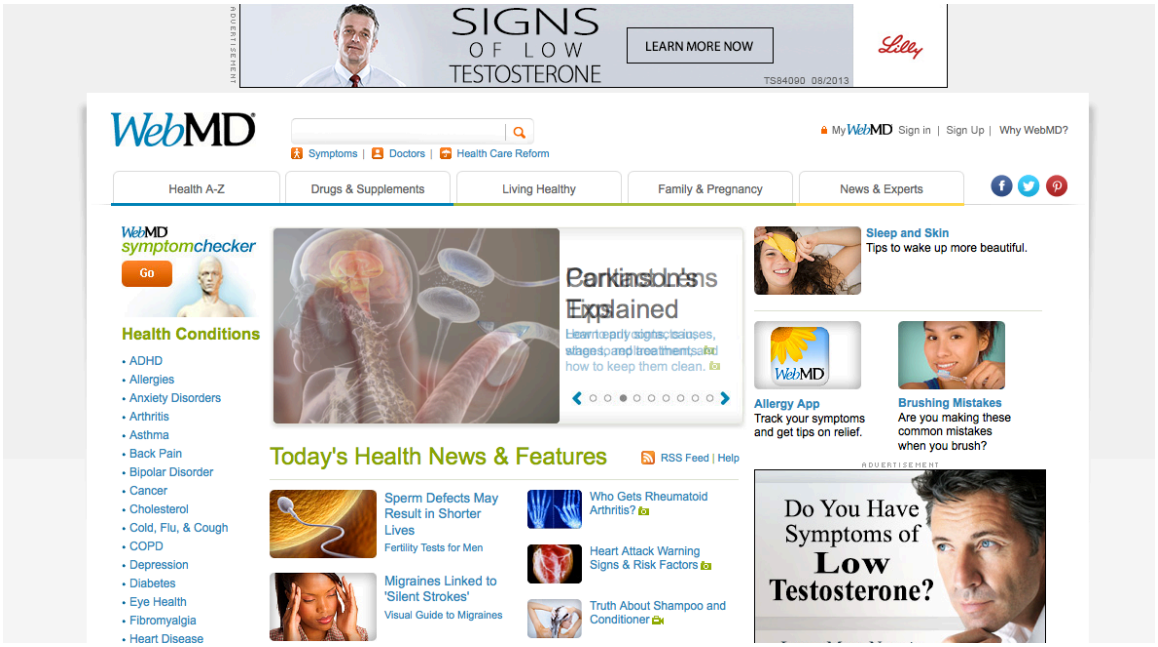


Figure 5: Old WebMD homepage (Summer 2014)

The (current) WebMD homepage (see Figure 4) is designed somewhat like a news site, with a main article as the focal point of the page, a video at the right, and other recent news stories just below it. The homepage is divided into multiple sections as one scrolls down. One section is labeled “Conversations,” which displays a selection of WebMD’s recent social media posts (see Figure 6). When WebMD redesigned its site from summer 2014 to fall 2014, one of the major changes was to place much more emphasis on social media. This emphasis shows a move towards a social media presence as an important part of a credible ethos: Having over a million Twitter followers (as is the case with WebMD) serves as a modern-day form of an age-old contributor to trust, social validation. At the same time, the Conversations section showcases WebMD’s affiliations with celebrities and other trusted organizations and news outlets and shows WebMD to be up-to-the minute with updates and content.

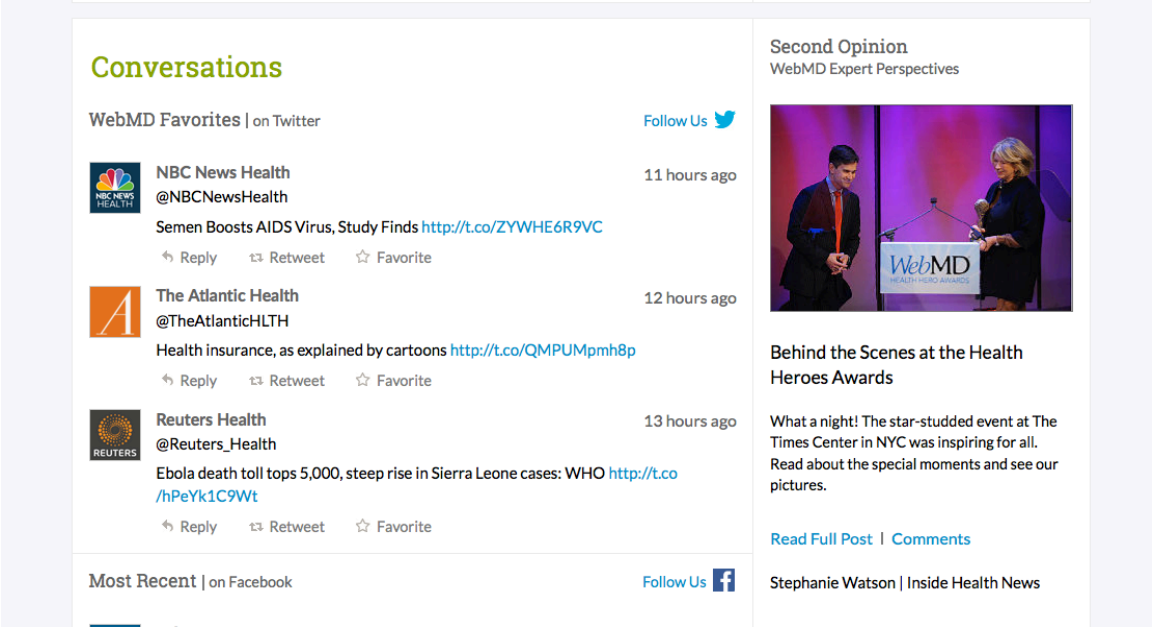


Figure 6: WebMD "Conversations"

Below the Conversations section are articles on general healthy living, articles on specific medical topics, and interactive tools. The articles, topics, and tools are

diverse. For example, article titles include “Multiple sclerosis facts,” “Recipe of the day,” “Detergent pods a poisoning threat for kids,” and “Benzodiazepines: Are they safe?” It is clear that the audience is broad – the articles are similar to what one might find in a health magazine, dealing with generic topics like weight loss, recipes, and “fun facts.” It is possible that this breadth of content, placing celebrity diet tricks next to informational articles about serious diseases, makes the site appear less purposeful and focused, which could detract from its credibility. Excessive ads, commercialism, and overall “clutter” have been found to detract from credibility on websites (Fogg, 2002); another change with the redesign, as can be seen in Figure 4 above, involved streamlining the information on the page and providing more white space. The website is still highly visual, with an image associated with nearly every article.

At the bottom is WebMD’s A-Z health topics glossary, a section labeled “Health Solutions from our Sponsors,” more links to WebMD social media pages and corporate information, and third-party guarantees such as the URAC (a health accrediting company) seal, the TRUSTe seal for compliance with a privacy program, and the HON (Health on the Net) Code (see Figure 7). While sections like “Health Solutions from our Sponsors” could be seen as insincere, the trust seals instead signal credibility. They help to show the site as trustworthy in the areas of protection of user data and quality of health information. The fact that third-party evaluators, not just WebMD itself, have vouched for WebMD in these areas makes it especially credible.

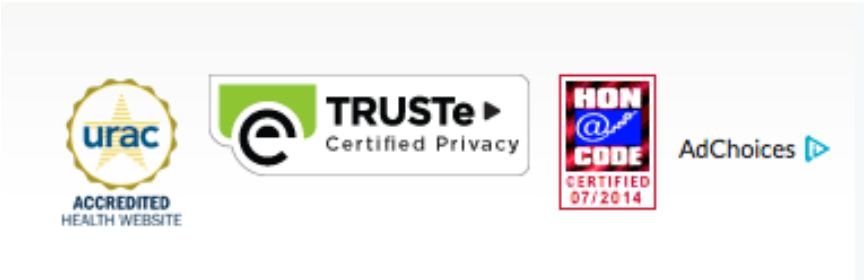


Figure 7: WebMD third-party seals

Another notable feature accessible from the homepage is the Symptom Checker (see Figure 8), one of WebMD's most popular interactive tools. It lists possible causes for the symptoms that users have checked, provides contact information for local doctors, and invites users to join relevant WebMD Communities.

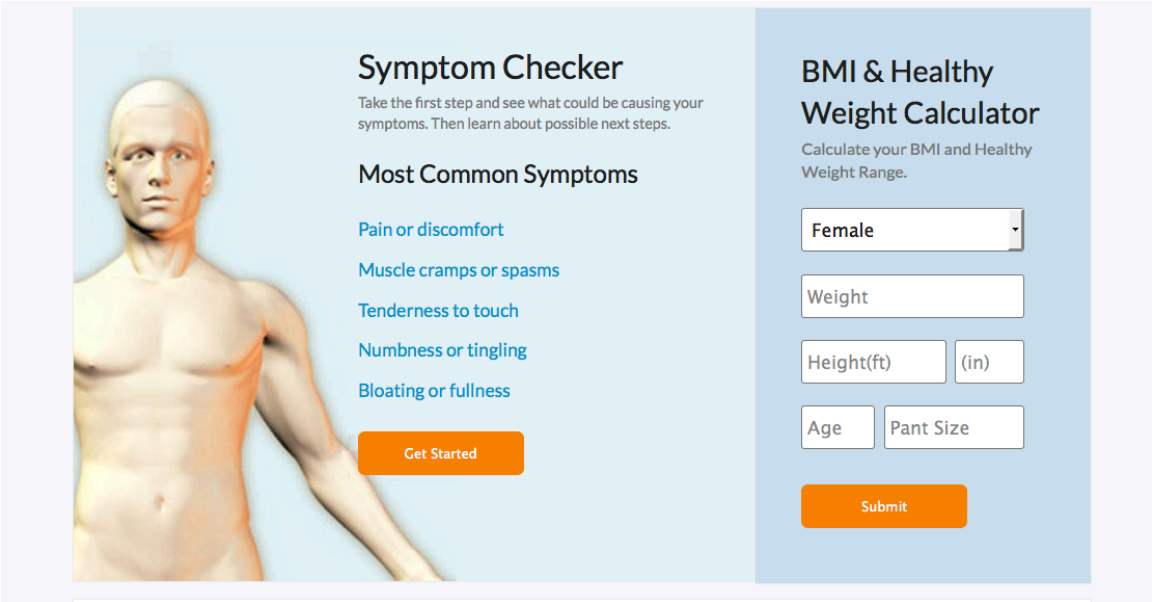


Figure 8: WebMD Symptom Checker

While the tools on WebMD such as the Symptom Checker or the BMI calculator are interactive, they only enable interaction between the user and the website – they do not encourage participation between the user and others. And while the community feature enables interaction among peers, this feature is not well advertised and is not accessible from the homepage, at least without being logged in. There are two types of

communities offered: member-created and WebMD-moderated. This suggests that the credibility and value of the community still comes, at least in part, from medical expertise (as will be discussed in more detail in Chapter 6).

While the commercialism of the WebMD homepage detracts from its credibility, the website succeeds in ways that NIH.gov does not: WebMD keeps users central by offering ways to personalize the experience such as the Symptom Checker. Multiple access points to health information (search box, featured health topics, Health A-Z) reinforce that the intended audience is the lay information searcher.

It is on the WebMD About page (see Figure 9) where the company starts to be more intentional about shaping its ethos as a credible source of health information, not just as a useful, broad, or entertaining source. The About page uses headings such as “Our award winning content,” “Our Policies,” and “How to Contact Us,” and uses corresponding visuals such as a stethoscope, employees in suits, and a trophy, all of which form a picture of WebMD as a quality-focused medical organization.

Figure 9: WebMD About page

At the top, it lists its mission: "WebMD provides valuable health information, tools for managing your health, and support to those who seek information. You can trust that our content is timely and credible." This mission statement is set apart in a box, making it the focal point of the page. The mission statement links prominently to another page, "What We Do for Our Users." The "What We Do for Our Users" page is primarily text-based, explicitly communicating what WebMD values and what it expects users to value. Several of the values cited in this webpage connect directly to credibility and information quality:

- Credible ("we provide credible information")
- Depth ("in-depth reference material")
- Relevance ("subjects that matter to you")
- Timeliness/currency
- Familiarity ("well known content providers")

- Expertise/expert review
- Interactivity
- Credentials (employees have verified advanced academic and medical degrees)
- Integrity of editorial process
- Entertainment (set in contrast to credibility: “As serious as we are about credibility, we also know that at times, health information can and should be engaging, exciting, and entertaining”)

Under the heading “Awards and Recognition,” it reads: “WebMD offers credible and in-depth medical news, features, reference material…We are proud that others in the fields of media and health have recognized our efforts.” On the right is a box indicating WebMD’s URAC website accreditation, a larger version of what was featured on the homepage. From here, one can click to “Find out how WebMD ensures the quality, accuracy and security of our information.” So, while WebMD has made claims about its credibility in its “What We Do for Our Users” page, it has also highlighted how others have independently accredited or affirmed the quality of the site by drawing attention to awards and to the third-party seals.

The About page also links to employee biographies, which feature the four main medical editors, as well as senior editorial staff. The page description states that WebMD works with over 100 doctors and health experts to ensure “up to date, accurate” content. Doctors are showcased on the “Who We Are” page, but there is no sense of who founded the company or who the president or CEO is, and it is difficult, if not impossible, to find this information on the site.

All of the medical editors have MD next to their names. The biographies are written in third person, and describe the employees' academic and medical backgrounds, as well as relevant volunteering experience. All of the four main doctors have made appearances in popular media outlets. The information about medical and educational credentials is an expected credibility appeal for a medical information website; the information about the doctors' popular media appearances serves WebMD's secondary purpose of being entertaining and having broad appeal.

These biographies are significant on WebMD because many of the WebMD medical articles are hyperlinked to their reviewers' biographies. Unlike much easily accessible medical information on the web, articles on WebMD indicate both a writer and a reviewer, and the hyperlinks enable readers to directly review their biographies and credentials. It seems that WebMD, by so explicitly emphasizing the quality, accuracy, and credibility of its information, is setting itself apart from unverified and low-quality health information on the internet. These overt links to credentialed authorship help to support WebMD's claims of information quality.

The About page also includes a list of policies and disclosures, such as the privacy policy. It states, "We understand that health is a very personal, private subject," and that "we respect your privacy choices." Like on NIH.gov, the privacy policy assumes that privacy is important to its users. It includes its accreditation and privacy seals yet again at the bottom of the privacy policy.

In summary, WebMD's main role is to serve as a health news and information site, and credibility is enhanced through repeated references to its expert medical doctors and quality review process, and in third-party quality and trust seals repeated throughout the website. Meanwhile, in the design of the site, WebMD strives to make

their content relevant and accessible for a lay reader; the user-centeredness is reflected in the breadth of topics for audiences and the options for customizing information beyond just searching and browsing. The expert-authored information is the hallmark of the site, but WebMD opens up some options for more user participation by having a sign-in option and WebMD Communities, some of which are expert-moderated and some of which are member-created. So, while WebMD's ethos is ultimately a professional, expert one, as suggested by the "MD" in its title, it also has moved in a more user-centered direction.

PLM's Organizational Information Pages

A look at a medical social networking site can show how credibility operates in a predominantly peer-to-peer space. PLM's visual and information design features make the site visually engaging and navigable, while also placing the website in the category of a social network site. At first glance, PLM's homepage (see Figure 10) is very clean and uncluttered – the background is white at the top, fading into a light blue on the bottom. There are no advertisements.

Figure 10: PLM homepage, part 1

The most prominent visual feature is the enlarged play button above the slogan "Live better, together!" Below the slogan, it reads, "Making healthcare better for everyone through sharing, support, and research." The slogan and play button are superimposed on a faded, blue and green background image of eight adults holding hands. The green "Join now" button below the slogan is also a central feature of the page.

At the top left of the webpage are the company name and a search bar, inviting searches for conditions, symptoms, and treatments. At the top right are the sign-in fields. Below the video link and "Join now" button are three icons, with descriptions for actions people can take with the site, such as "Connect with people like you."

Like many social networking site homepages, PLM's homepage serves as a "front page" meant to acquaint users with the purpose and benefits of the site, and to emphasize the importance of becoming a member in order to experience those benefits. While many social networking sites use design features and visual emphasis to guide the user to sign-in fields to create an account, PLM's focal point is, instead, the play button. To press the "Join now" button, placed below the video, seems like a natural next step after viewing the video, which showcases members explaining the benefits of joining the site. To prioritize an informative video about the website makes sense, given that PLM is an unconventional e-health site – it has more persuasive work to do before users will buy into the company's mission.

Scrolling down (see Figure 11) reveals three columns. On the left is a video titled "Member stories" (the same video that is the focal point of the page). In the center is a brief history of PLM including a photo of the co-founders with their brother with ALS. On the right are news stories about PLM, which link to a PLM press page. Below that

are statistics pertaining to the site (250,000+ members, 2,000+ conditions, 50+ published research studies, 22 million data points about disease). The statistic about published research suggests that PLM is aligning itself with the credibility of peer-reviewed, published studies. Listed along the bottom are the main categories with information about the site, grouped on the left and right sides of the page.

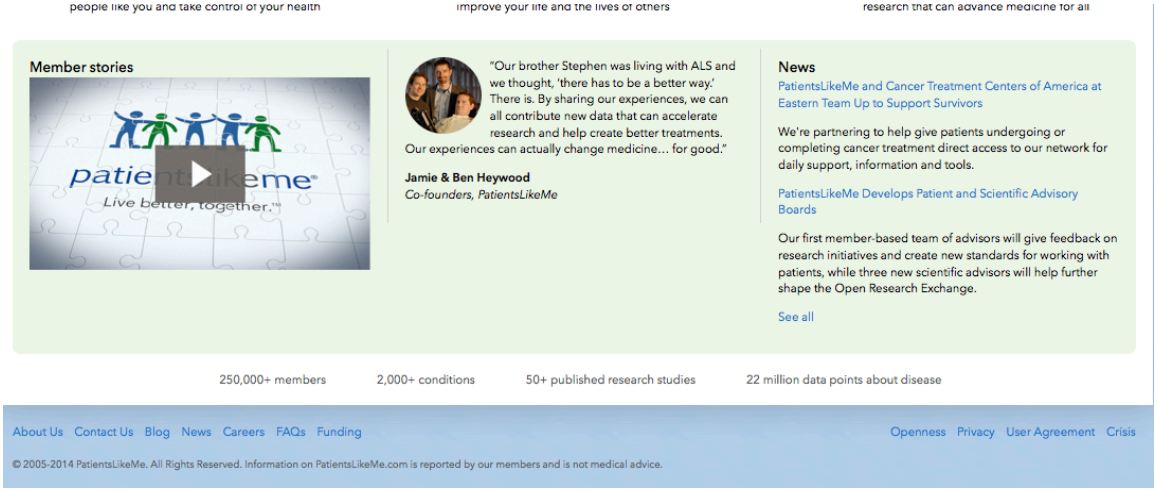


Figure 11: PLM homepage, part 2

The homepage is designed in such a way as to encourage users to take certain actions. A very important contrast from NIH.gov and WebMD is that, from the homepage, there is no main menu to organize the site, so it is clear that this is not a standard site for browsing information. Instead, the options for users' actions include joining the site (or signing in if already a member), searching in the search box, or learning about the company through playing the video or clicking on the links at the bottom of the page, which include About Us, Contact Us, Openness, and Privacy. The links serve a number of purposes: First, links to recognizable webpage genres like the About page feel familiar and make it easy for users to find company information. On the other hand, the presence of unusual links like "Openness" suggests ways in which the site is unique.

Once a user clicks on one of these pages, such as the About page, they are brought inside the site, which uses an established page design. This design consists of menus across the top, left, and bottom, surrounding the central content of the page (see Figure 12). The links along the top (Patients, Conditions, Treatments, Symptoms, and Research) lead users to the core features of the site. The links along the left lead to corporate information such as PLM's "Our Team" page, Openness Philosophy, Investors, Partners, Press, Testimonials, and Careers.

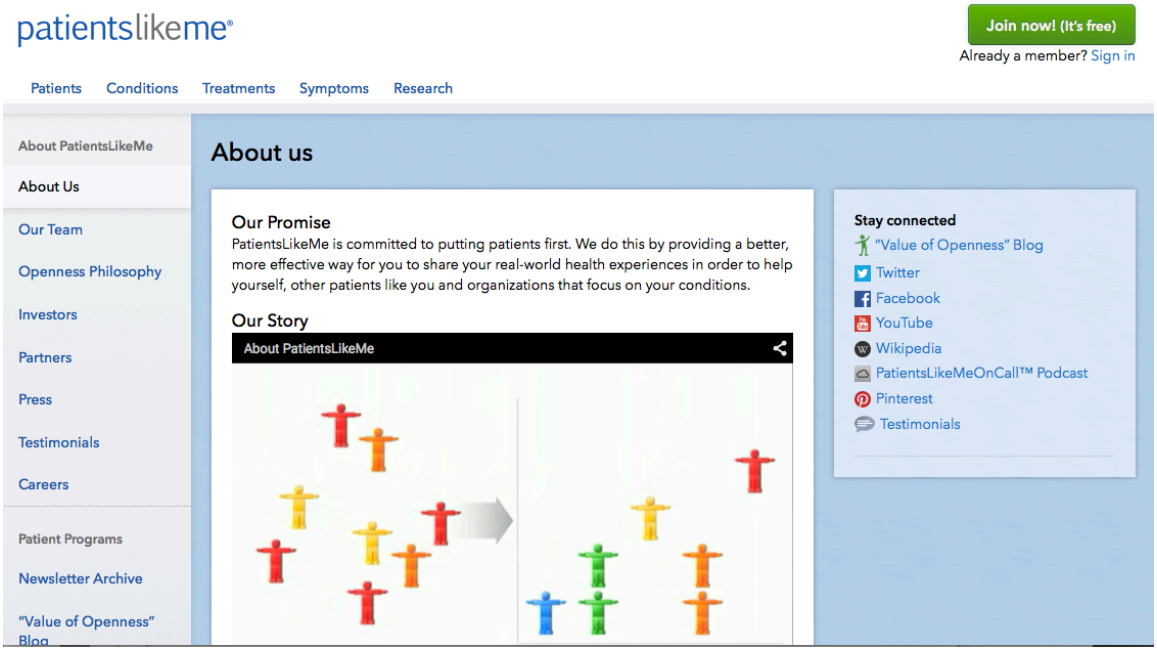


Figure 12: PLM About page

There are several visual elements from the homepage that are carried throughout the rest of the website. For example, the cool color scheme, consisting of light blue, green, gray, and white, is repeated throughout the pages.[28] The name "patientslikeme" is repeated in the top left corner of each page, helping to establish the company's brand, with the lower-case initial letter giving an informal feel. Another

[28] Some research in HCI has found that users find cool, pastel color schemes to be more credible in websites (Wang & Emurian, 2005).

repeated visual element is the green “Join now (It’s free!)” box, which is placed in the center of the homepage as well as in the top right corner of the other webpages. This consistency and brand convey professionalism and familiarity.

Along with design features, PLM signals credibility by “borrowing” from the credibility of recognized organizations. As the other two e-health sites also do, PLM draws attention to its affiliations with other credible or familiar organizations, whether medical and research organizations, media organizations, or social media websites.

First, PLM’s associations with research and medical organizations align it with traditional scientific and medical authority. For instance, the homepage features a “News” column, linking to a press release titled, “PatientsLikeMe and Cancer Treatment Centers of America at Eastern Regional Medical Center Team up to Support Survivors.” The fact that a medical institution has partnered with PLM suggests that PLM is accepted even within the mainstream medical system. One of the co-founders, Jamie Heywood, mentions in his profile the nonprofit medical research groups Augie’s Quest, the Muscular Dystrophy Association, and, most importantly, the ALS Therapy Development Institute, which he founded. He says it “has become widely recognized as one of the most promising and innovative research organizations.” The textual description of PLM on the About page reads that PLM works with “trusted nonprofit, research and industry partners who use this health data to improve products, services and care for patients.” This statement highlights that PLM considers these organizations to be trustworthy, and that they have patients’ best interests at heart. These references build on the credibility of the mainstream medical system while also aligning with the innovative, independent spirit of grassroots research groups.

PLM also leverages its affiliations with popular media publications and organizations to boost credibility. For instance, the "Our story" video is interspersed with clips from a TED Talk[29] by Jamie Heywood. In their biographies, the Heywoods reference popular media accounts of their family's experience with their brother's ALS prior to PLM, including a book written by a Pulitzer-prize winning author and a documentary that was featured at the Sundance Film Festival. Their family was profiled in the *New Yorker* and *60 Minutes*. These sources refer to Jamie as a "guerilla scientist." Unlike the affiliations highlighted by NIH.gov and WebMD, these media affiliations do not draw as much from traditional contributors to credibility such as expertise; rather, they function more to develop the founders' sincerity – to present their family's story as a compelling motivation for starting the company, and as remarkable and touching enough to receive attention from well-known media outlets.

In addition, the inclusion of a prominent social media block, labeled "Stay connected," shows that PLM, like NIH.gov and WebMD, has a broad social media presence, with links to their pages on Twitter, Facebook, YouTube, Wikipedia, and Pinterest. The list also includes links to pages within PLM's own website, such as their "Value of Openness" blog, podcast, and testimonials. PLM's social media block provides a variety of spaces to feature patient voices: While some are filtered through PLM, such as the testimonials page and YouTube page of professionally made video interviews with users, PLM also shows itself to be open to communicating with its users via informal avenues like Twitter or YouTube comments. At the bottom of the block is a "Share this" button which makes it easy for their pages, such as the About page or

[29] TED is a nonprofit that hosts conferences on topics of technology, entertainment, and design.

Openness Philosophy, to be shared via many social media sites. PLM's social media presence shows that PLM is a web-savvy company that is followed by thousands across several well-known social media sites.

By far the most salient contributor to the company's personal ethos, which was not as well emphasized in the other websites, is representations of people. While NIH.gov and WebMD are loaded with articles and news stories, PLM's mode of choice for conveying information is videos of interviews with patients, quotations, and narratives. PLM conveys a message of concern for its users as individuals, while helping those individuals to see themselves as part of a larger community with a larger purpose. For example, the "Member stories" video, the focal point of the homepage, draws attention to real users of the site. This video is one of many strategies PLM uses to create a sense of personal relationship with users. The video opens with users' profile photos on puzzle pieces, falling into place, while voiceovers consist of patients describing feeling fear, dissatisfaction with the information from their doctor, and lack of community. Then, real users introduce themselves; they consist of a mix of ages, genders, and conditions (psoriasis, MS, Parkinson's, and epilepsy). By showing real patients who have benefited from the site, potential users can imagine themselves in the position of these patients.

PLM further displays concern for the individual by talking about specific users in a different video, the "Our story" video on the About page. The opening of the video includes clips of everyday PLM users and supporters, participating in a PLM-sponsored race. Ben Heywood, the other co-founder, talks about the early days of the company, and recalls one of the earliest members of the ALS community by name. Ben Heywood says, "getting the first patient to sign up and use the site was awesome." He also tells a

story about meeting a user in person, who shared that the site was meaningful to her. He is emotional while sharing this anecdote, showing care and concern for the site's users. PLM also makes explicit their appreciation for patients by stating on their About page, under "Our promise," that they are "committed to putting patients first." While this might seem like an empty claim by itself, the use of images, video, and personal narrative to highlight specific past and present users and experiences presents PLM as a company that lives up to its word.

Within the PLM webpages analyzed, the references to doctors and physicians are few; one PLM user in the opening video talked about doctors "giving very vague answers" and how using PLM helped her to find answers she needed about her disease. The only other references to doctors had to do with sharing data with them; Jamie Heywood, in his personal profile, talked about how the ALS research institute openly posted their research results to share with doctors, which is a reversal of the typical clinical research model in which results are protected. Moreover, the Openness Philosophy says that patients' data belongs to patients to share with doctors to "improve dialogue." While doctors are not ignored by PLM, doctor expertise is not used as a primary credibility-building strategy. Doctors factor into the equation only to the extent that patients choose to include them by sharing their data; in fact, PLM's message is that patients are empowered by owning the data that they track and generate, which reverses the traditional information hierarchy in which medical institutions are the primary holders of patient data.

PLM effectively balances the emphasis on individual empowerment with a sense of community. Many of the references to people, whether in text, video, or image, portray them in community or relationship, displaying the participatory nature of the

site. For example, two of the three main actions listed on the homepage are relational: “learn from others” and “connect with people like you.” Even the corresponding images, of a speech bubble and of two stick figures standing together, convey a social aspect, with patients at the center.

In addition, the homepage emphasizes the social: The company name, slogan, and background image of people holding hands all support the message of community. The “Member stories” video (which appears twice) illustrates the relationship between the individual and the community very well: It opens with puzzle pieces, which each have pictures of individual users, falling into place to form a larger whole. As mentioned above, the video features interviews with individual users talking about their own experiences and about feeling alone, but as the video progresses, they talk about how they transformed their individual challenges into opportunities to help others. One user talks about “the chance to help someone who has psoriasis like me to live a little bit of a better life,” appealing to altruism.

Besides talking about giving and receiving help from other “users like them,” the patients in the video also talk about an even broader community, joining in the overarching goal of finding treatments and cures on a large scale. The third main action listed on the homepage is “track your health,” with an image of a line graph. While this is not a directly relational action like the other two, the description says, “Chart your health over time and contribute to research that can advance medicine for all.” In other words, even actions that have immediate personal benefit can be leveraged to advance clinical research as a whole. Similarly, in the “Member stories” video, one patient says, “we can do much better fighting the disease as a group than we can as individuals.” This talk about the advancement of research and medicine sounds reminiscent of the

NIH's mission, but it keeps patients at the center – as the agents and the beneficiaries of the advancement.

The emphasis on "the greater good" carries through explicitly in the About pages, the co-founder profiles, and the Openness Philosophy. In the "Our story" video, clips of Jamie's TED Talk are shown, with him sharing his vision for PLM. He says, "we need to give to others to be successful." In the Openness Philosophy, the pronouns "we" and "our" are often used, including a reference to "our collective knowledge." It concludes with the goal of "bringing people together for a greater purpose." This theme of the greater good and a common vision comes through even in the privacy policy, which, interestingly, opens with a statement about its openness and how a "shared belief" in openness contributes to "collective knowledge" on disease and health.

PLM as a company constructs its patients as important both for their individual stories and as contributors to a larger mission; the company also strategically constructs itself in relation to those patients to convey their sincerity and caring. For instance, Ben and Jamie Heywood are represented via video, photograph, and text across the homepage, About page, and employee bios, showing PLM to be not an impersonal company, but a company with real people and a history behind it. In addition, the use of personal pronouns throughout the site, such as titling the About page "About us" with subheadings like "Our promise" and "Our story," make the site feel personal and create a sense of ownership.

The Heywoods' employee profiles are particularly telling in terms of how PLM's credibility strategies stand out. Jamie's profile is written in first person and includes a few mistakes. On WebMD or NIH.gov, errors like this would surely detract from credibility, but in the greater context of PLM's personal ethos, such errors instead make

Jamie appear relatable. Additionally, instead of medical degrees and credentials in their profiles, the Heywoods tell the story of their brother, and how witnessing his experience of ALS drove them to start PLM. Moreover, in the "Our story" video, they are both interviewed in casual settings within the PLM office, helping to show PLM as a real place and the Heywoods as real, approachable people. At the same time, the Heywoods position users as innovators, along on a shared journey with them. As Jamie says in his TED talk, excerpted in the "Our story" video, "Our patients have really put a lot of trust in the community and us as a company to work with them on that journey… It is a core value of our company to honor the trust that our patients are putting in us."

In summary, PLM does rely somewhat on scientific or medical expertise to build up their credibility, just as NIH.gov and WebMD do. For example, they highlight affiliations with credible medical institutions. But, if there is an expertise that is predominant here, it is of an unconventionally valued type – that of the patient. For example, PLM treats individual patient experience as valid information, as shown by the patient testimonials, the linking back and forth between individual patients and the larger whole, and even in the emphasis on the Heywoods' personal narrative.

Indeed, throughout the site, PLM builds credibility not through expertise but through sincerity, community, and showing concern for patients as people. PLM uniquely focuses on its co-founders, not by drawing attention to a PhD or MD behind their name, but by drawing attention to their personal narrative and their fight to extend their brother's life.

PLM also constructs a community by presenting the co-founders and users as fighting a fight together, not only against disease, but against the established, slow, closed system of clinical research, and against a medical system that views patients as

numbers rather than as people. In one sense, this rhetorical move may be seen as capitalizing on recent growing distrust in authority; more broadly, it may also be about how the internet has led to a growing expectation of access to areas that were traditionally the domain of experts. PLM is, perhaps, establishing an overall patient-centered, participatory ethos that works against that of the mainstream medical system, characterized by problem-solving and efficiency and not necessarily personal connection.

Conclusion

All three organizations – NIH.gov, WebMD, and PLM – have textual, visual, and even interactive features on their websites that signal their credibility to form a successful ethos. In fact, the websites are similar in many ways: They are all highly visual, hypertextual, generally well-designed, and well-maintained. All of the websites are reasonably easy to navigate and meet basic, common criteria for website credibility; for instance, each has an easily accessible privacy policy and shows that their website is updated frequently.

All of the websites emphasize, to some extent, the credibility inherent in peer-reviewed or expert-reviewed content, and all of them use the strategy of highlighting affiliations with well-recognized organizations. Each of the e-health websites has a strong social media presence that is quickly noticeable from their respective homepages. Displaying the connections to other social media sites may be a new type of contributor to e-health sites' credibility, and is a sign that the web, in general, is growing towards the social.

There are, however, important ways in which each website's credibility strategies differ. While both NIH.gov and WebMD accentuate expertise, NIH.gov does

so through its history and scientific and governmental authority. WebMD, on the other hand, accentuates the expertise of its physicians and reviewers and makes explicit arguments about the quality of its information. At the same time, WebMD moves in a more personal direction, offering more opportunities for interaction. PLM builds on the more traditional credibility features used in medical information, but also emphasizes the sincerity of the site creators and the experience of individual patients. Therefore, while PLM does not rely upon researcher or physician expertise, it grants patients their own type of expertise. The employee profiles on NIH.gov and WebMD both emphasize credentials, with the WebMD profiles showing more of a personal side. PLM's profiles take the personal aspect a step further present the company's co-founders as people to identify with.

On NIH.gov and WebMD, the main features on the homepage are the articles, implicitly communicating the websites' purpose as repositories of information. However, WebMD, in including communities, topics of broad interest, and interactive tools, serves as a hybrid site that encourages greater user engagement. PLM also encourages user engagement, but on a broader scale: Connection is not simply an added feature but is the core of the site.

This analysis shows a range of e-health sites and the range of credibility features used to construct a successful ethos. Unidirectional information sites like NIH.gov may represent the standard model for health information, positioning patients as consumers and projecting an official governmental, scientific ethos. WebMD, with its ethos of professional expertise balanced with user-friendliness, and PLM, with its personal, communal ethos, both display how some websites are starting to shift that structure, positioning patients as active participants.

This chapter has focused on e-health websites' construction of a credible ethos in their organizational information pages as a means of promoting trust in their site. Ethos shapes people's perceptions of an organization and whether they will engage with the website's information on a deeper level. So what happens when we look inside each website, when we peel back the first layer examined here? To help answer this question, the following chapter compares the credibility features of the Parkinson's information pages published by each organization.

Chapter 5: Credibility in Medical Information Webpages

As shown in Chapter 4, e-health sites work to establish trust by constructing a credible ethos in their organizational information pages. These pages are obvious places to project an organization's identity and character. However, an organization must continue to establish trust all throughout its website, especially in the information that patients may use to make medical decisions. Studies of trust and e-health have shown that "the quality of information on e-heath websites is crucial for the development of trust in e-health services… Users of e-health sites trusted sites that can demonstrate in-depth knowledge of a wide variety of relevant topics and deliver clear information" (Beldad et al., 2010, p. 861). In other words, information credibility features, likely more than an organization's ethos, play a strong role in establishing trust in the medical information pages of an e-health website. Medical information credibility initiatives have focused on criteria such as accuracy, authority, currency, depth, and objectivity.

Therefore, this chapter goes a layer deeper into the e-health sites in order to analyze medical information pages about Parkinson's disease within NIH.gov, WebMD, and PatientsLikeMe.com in terms of their credibility features. It is well known that patients today search for medical information online and consult multiple sources when they do so. There exists a broad range of medical information on the web, some of which is credible in more traditional ways, and some of which is adapting those older forms of credibility to reflect the social, sharing nature of Web 2.0.

As will be shown in this chapter, while each set of information pages shares the purpose of informing patients about the basics of Parkinson's disease, each differs in terms of usability, visuals, writing style, and citation of authorities, signaling how

credibility is built up uniquely according to the type of website. NIH information clearly displays its connection to standard, trusted procedures for generating medical knowledge; WebMD moves in a more patient-centered direction while setting a foundation of physician authority; PLM appeals to scientific as well as humanistic forms of credibility, placing the individual patient experience within the context of scientific visuals.

NIH.gov's PubMed Health Parkinson's Disease Information Pages

As noted in Chapter 3, NIH.gov acts as a portal website, collecting many government-based health resources. Searching "Parkinson's disease" from the NIH.gov homepage leads to a list of these resources (see Figure 13). The main Parkinson's information pages published by the NIH appear on the databases PubMed Health and Medline Plus (which are both services provided by the National Library of Medicine, one of the NIH's institutes). There are also Parkinson's information pages published by other institutes or centers of the NIH, including the National Institute of Neurological Disorders and Stroke, the Office of Genetic and Rare Diseases, and the National Institute of Environmental Health Sciences.

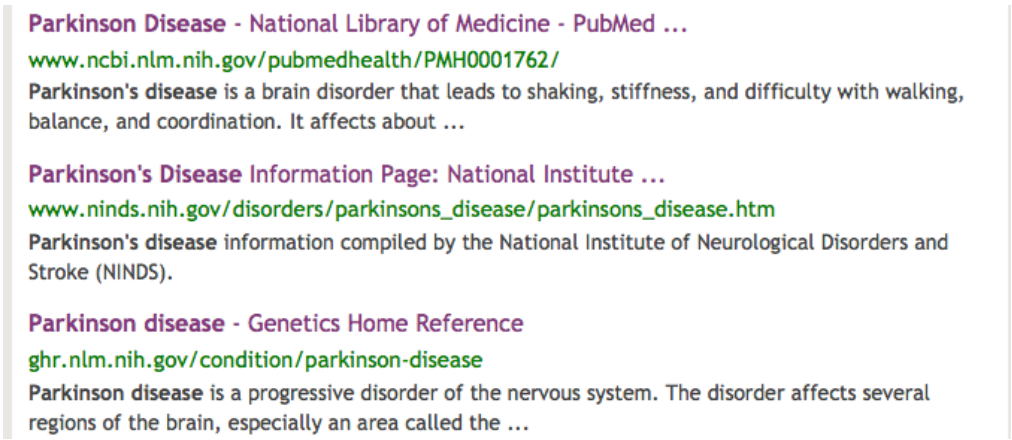


Figure 13: Sample of NIH.gov Parkinson's search results

This list of sources from a variety of government databases and research institutes helps convey the breadth and depth of the NIH's resources. However, as is clear from Figure 13 above, it is difficult to ascertain how the sources differ (there is much duplicated information) and where one might begin if they are seeking relevant and credible information about Parkinson's. Some sources seem more targeted to clinicians or researchers while others seem more targeted to patients, and there is not a clear sense of hierarchy for how to approach them. As was the case with the NIH.gov homepage, the unclearly-defined audience makes the information and the interface less usable. Nevertheless, a classic rule of credibility assessment is to verify information by checking multiple other sources, and this access to multiple sources provides ample opportunity for cross-checking, at least within government-approved sources.

The PubMed Health entry for Parkinson's, which was highly-ranked in the search results and is targeted to consumers and clinicians, provides more insight into how the NIH's credibility operates. The PubMed Health information pages on Parkinson's include a glossary page and an overview page.

The glossary entry for Parkinson's is primarily textual. It defines Parkinson's disease as "A progressive disorder of the nervous system marked by muscle tremors, muscle rigidity, decreased mobility, stooped posture, slow voluntary movements, and a mask-like facial expression," and then cites the source of the definition, the NIH National Cancer Institute. The text, at times, includes some technical terms that might be hard to understand, but provides multiple ways for readers to learn them. For instance, there is a hyperlink from the word "tremors" to a page defining tremors, and at the bottom of the page is a glossary briefly defining other terms to know, including "bradykinesia" and "dyskinesia." At times the textual description includes definitions

within the text, for instance, “Parkinson’s is a progressive disease, which means that in most cases it will continue to gradually get worse.” Overall, the writing style balances medical jargon with explanations for lay users.

The main visual on the page is an illustration of a neuron with parts labeled (see Figure 14). The visual is not interactive, but one can find a fuller explanation of neurons by clicking on it. The graphic conveys intricacy while at the same time familiarity, as it resembles the type of illustration found in an anatomy textbook.

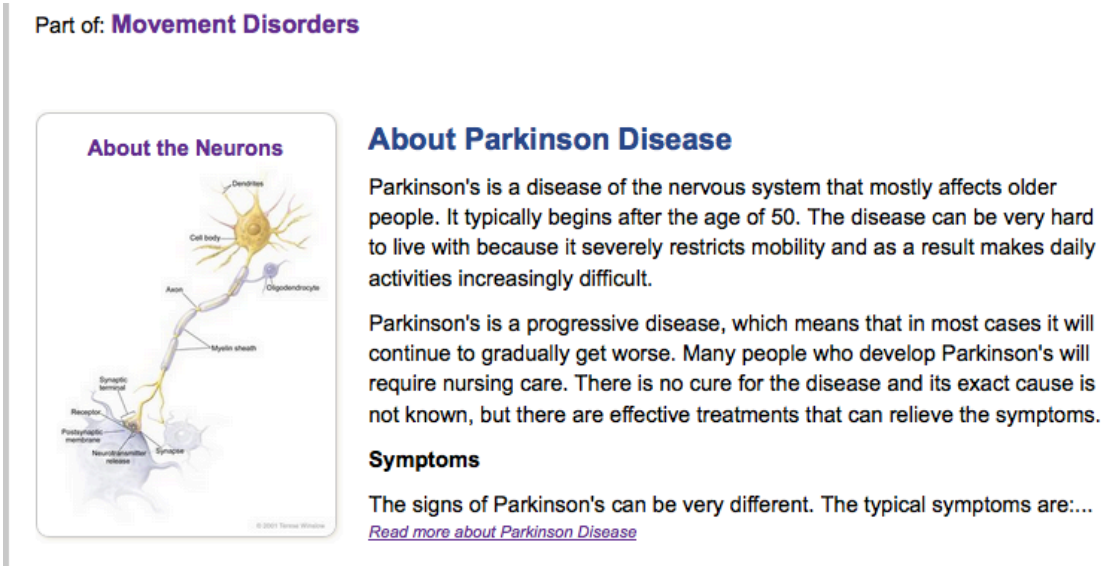


Figure 14: PubMed Health glossary entry for Parkinson's

The page also conveys credibility by emphasizing the organization’s identity. In the top left corner is a link to the U.S. National Library of Medicine, described as “the world’s largest medical library.” In the bottom right corner are the logos and links to the National Library of Medicine, NIH, etc. (see Figure 15). These logos emphasize the information’s relationship to multiple governmental organizations. In this way, the official, scientific ethos the NIH has established in its homepage, About page, and other organizational information pages can be carried through and connected with the

information itself. In addition, there are no advertisements found on the information pages, making it seem relatively objective.

Figure 15: Organization logos on PubMed Health Parkinson's pages

There is also a section on the page labeled, “What works? Research summarized.” There are links to both “Evidence reviews” (155 total) and “Summaries for consumers” (37 total), several of which have highly technical titles, such as “Pergolide versus bromocriptine for levodopa-induced complications in Parkinson’s disease.” The technical medical terminology may not be accessible to all readers, but the specialized vocabulary conveys scientific expertise. The fact that there are more reviews for clinicians than patients suggests that clinicians may be a more targeted audience for this information, while patients are a secondary audience.

The page of evidence reviews includes abstracts with citations to full studies. These studies are not standalone clinical research studies, but rather syntheses of existing studies. At the bottom of each summary, it reads “this article meets the DARE [Database of Abstracts of Reviews of Effects] scientific quality criteria for a systematic review.” These criteria relate to the methodological rigor and detail of the synthesis studies.

The page of consumer summaries includes abstracts, written in plain language, of various synthesis studies. The abstracts are broken up into sections such as methods and results, and occasionally use passive voice, signaling these studies’ alignment with the scientific article genre. The full studies and their authors are clearly

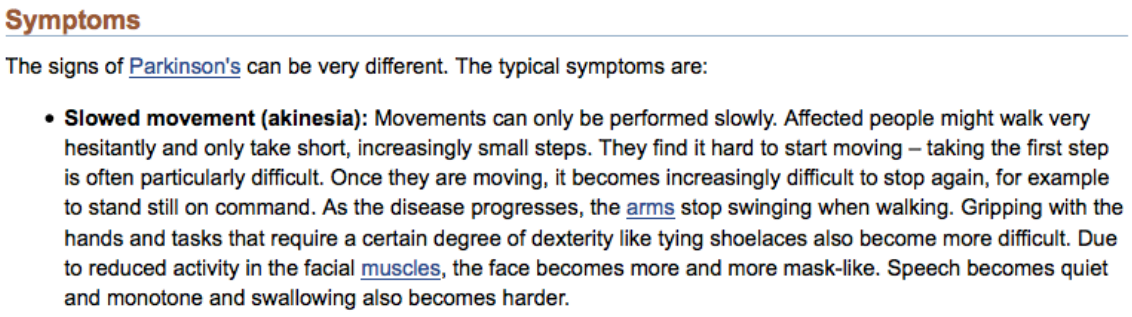
cited, showing care for thorough documentation and providing a path for readers to trace back to the original authors of the information.

At the top of the page is information about currency. For instance, one of the studies was published in 2009, but there is also a note that "Review content assessed as up-to-date: November 30, 1998." Given the speed with which medical information changes, this seems rather out-of-date. Nonetheless, the fact that the date is included at the top suggests the importance of considering the information's currency when assessing its credibility and usefulness.

This section of review studies (and that it is labeled "What works?") points to the value this organization places on establishing a baseline of accepted knowledge for treating Parkinson's. This knowledge is built up incrementally, as more and more methodologically-sound studies are conducted regarding treatment efficacy. The participants in these various trials add up to thousands. The underlying assumption is that more research over time provides greater confidence in claims of clinical effectiveness. There is no information about newer, untested therapies.

PubMed Health's information pages on Parkinson's also include an overview page. This page is only textual; no visuals are included. The page is organized into sections such as Introduction, Symptoms, Causes, Treatment, etc. and uses bullet points and hyperlinks to definitions throughout. This contributes to the readability and accessibility of otherwise rather technical information. There are no apparent errors or broken links in the text, signaling professionalism and accuracy. Symptoms and outlook are described in abstract, generalized terms, with patients addressed in third person, for example, "Fine motor skills typically deteriorate and handwriting changes. People sometimes lose their sense of rhythm or their arms no longer swing when walking."

Patients are addressed in second person in the diagnosis section, for instance, “the doctor will text your reflexes.” See Figure 16 for an example of the information design and writing style.



Symptoms

The signs of Parkinson's can be very different. The typical symptoms are:

- **Slowed movement (akinesia):** Movements can only be performed slowly. Affected people might walk very hesitantly and only take short, increasingly small steps. They find it hard to start moving – taking the first step is often particularly difficult. Once they are moving, it becomes increasingly difficult to stop again, for example to stand still on command. As the disease progresses, the arms stop swinging when walking. Gripping with the hands and tasks that require a certain degree of dexterity like tying shoelaces also become more difficult. Due to reduced activity in the facial muscles, the face becomes more and more mask-like. Speech becomes quiet and monotone and swallowing also becomes harder.

Figure 16: Part of PubMed Health overview page for Parkinson's

Treatments are also discussed in generalized terms – there are no specific brand names listed; rather, the overall goal of treatments is addressed. As an example, medication for Parkinson’s is described as aiming to replace missing dopamine in the brain. There is also a date at the top, stating that the most recent update was April 18, 2015, and the next update will be in 2018, again pointing to the importance of currency in light of the changing nature of medical information.

At the bottom is a list of sources, which includes studies published in well-recognized medical journals such as *British Medical Journal* and *Journal of the American Medical Association*, thereby invoking the credible ethos of the publications. The authors of the Parkinson’s overview page make an explicit appeal to the quality of their information:

> Our information is based on the results of good-quality studies. It is written by a team of health care professionals, scientists and editors, and reviewed by external experts. You can find a detailed description of how our health information is produced and updated in our methods.

Healthcare professionals, scientists, and editors are all considered expert authorities on the information; in addition, making available their methods for writing and updating content provides some transparency.

In summary, based on this small sample of some of the NIH's medical information pages about Parkinson's, the information conveys credibility in very familiar, traditionally successful ways for medical and scientific discourse: technical terminology to signal expertise, but balanced with definitions to provide greater readability; citations to published clinical trials and systematic reviews; an emphasis on high-quality, well-designed trials as the basis for knowledge about what treatments are effective for Parkinson's; and the explicit identification of medical experts as authors and reviewers of the information. The information is not as up-to-date as possible, but the fact that dates are included makes it simple for users to weigh the information's currency as they assess its overall credibility.

While there is some interactivity embedded in the webpages in that users can click to find definitions and more details, the information is otherwise quite static and text-based, much like one might find in a medical textbook or encyclopedia. The writing style is not particularly engaging, but its somewhat distanced, serious tone can contribute to the information's credibility. The design of the information is basic and uses recognizable document design features; it is situated within the context of a webpage with its governmental identity clearly indicated, reminding readers of the official ethos of the organization that stands behind the information.

WebMD's Parkinson's Disease Health Center

Information about Parkinson's disease on WebMD is housed within a page called the Parkinson's Disease Health Center (see Figure 17). The Center serves as a

starting point for exploring the multiple Parkinson's articles on the site. Unlike the search results on NIH.gov, the information is not authored by various groups with different audiences and agendas; instead, the articles are all clearly affiliated with WebMD and aimed at the consumer. A "breadcrumb trail" at the top situates the current page within the larger Brain and Nervous System Health Center. Articles are further categorized into "chapters" that address different aspects of Parkinson's such as "Overview and facts," "Symptoms and types," "Treatment and care," and "Living and managing." The breadth of topics addressed suggests that WebMD is not providing just clinical information but also advice, such as tips for traveling with Parkinson's. The chapters are accessible from a drop-down menu on the main page and from a menu on the left side. These various navigational tools create a sense of hierarchy for the information.

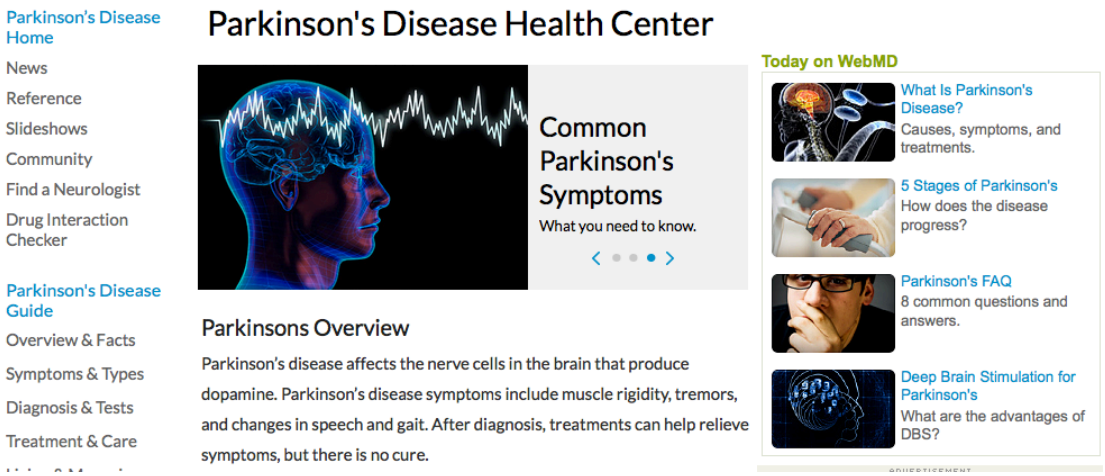


Figure 17: WebMD Parkinson's Disease Health Center

A brief overview defines Parkinson's in terms of its cause and symptoms: "Parkinson's disease affects the nerve cells in the brain that produce dopamine. Parkinson's disease symptoms include muscle rigidity, tremors, and changes in speech and gait." Clicking into the articles themselves provides more explanation of terms like

dopamine. Below the overview is a “Latest Headlines” section. The presence of news stories like “Parkinson’s protein may spur response” implies that WebMD stays current with medical research that sheds light on Parkinson’s disease, while headlines like “Ex-baseball star Kirk Gibson has Parkinson’s Disease” also suggest the breadth and personal tone of some of WebMD’s information.

Other sections of the main information page include links to discussions in the WebMD Parkinson’s Community and a list of top search terms for Parkinson’s disease. These two features introduce a more social variety of credibility. The links to discussions suggest that peer interaction is a valuable additional source for information on Parkinson’s. The search terms represent which topics are of most interest to WebMD users, thereby suggesting that others find WebMD to be useful and that a patient may find others’ questions and concerns to be a helpful approach to learning about the disease.

Two tools in the left column, “Find a Neurologist” (physician directory) and “Drug Interaction Checker,” enable users to input data such as their location or current medications and receive personalized information. The physician directory is a helpful, individualized tool but its presence also affirms the importance of a physician’s perspective on one’s medical condition, in keeping with WebMD’s main ethos of professional, physician authority.

As a whole, WebMD’s information is much more visual than the NIH information. There is a rotating slideshow of featured articles on the main page. In addition, one of the most prominent resources is “A Visual Guide to Parkinson’s Disease,” which is a slideshow with 24 images and corresponding information (see Figure 18). The slideshow serves as a broad overview of much of the information found in the text-

based articles on the site. For instance, there are slides about symptoms, early signs, progression, and diagnosis. Some of the slide titles are phrased as questions, such as "Who gets Parkinson's?" and "Can symptoms be prevented?" The information is quite accessible when broken up and accompanied by visuals.

Some of the graphics are scientific, such as computer-generated images of the brain or of the chemical structure of dopamine. Although these graphics are quite visually appealing, three-dimensional with bright colors, they are not integrated with the text in the standard manner for technical biomedical discourse. There are no captions, labels, or scientific explanations of the visuals in the text. This means that WebMD's visual information is perhaps "borrowing" from the air of scientific authority that comes with biomedical graphics, but without the corresponding depth. There are no charts or data visualizations.

Most of the non-scientific graphics in the slideshow are generic stock photos connected in some way to the information. There are several images of people in daily life, such as an older man holding a cup of tea, in connection with the slide on demographics (See Figure 18). Another image is of Michael J. Fox, a well-known actor and spokesperson for Parkinson's, in connection with the slide describing Parkinson's progression. This use of people-based imagery affirms that patients are the central audience.

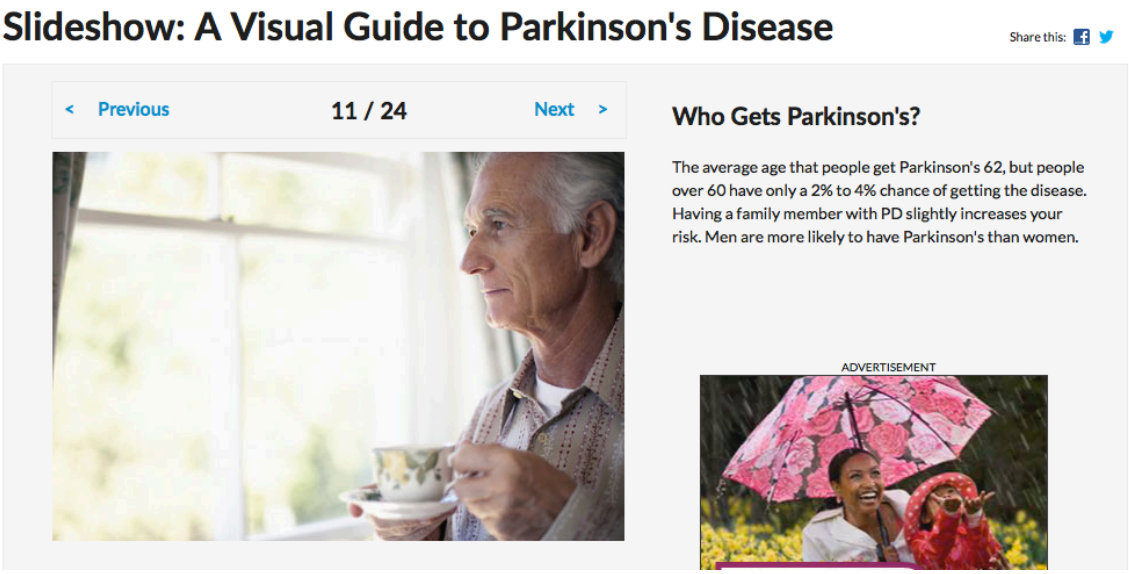


Figure 18: Example slide in WebMD Visual Guide to Parkinson's Disease

Although the visual nature of WebMD increases the engagement and accessibility of the information, it can also be distracting. Figure 18 above, with a pharmaceutical ad in the bottom right corner, shows the prominence of advertisements in WebMD content. Furthermore, on the main Parkinson's page, it is not always immediately apparent which information is an article and which is an advertisement. Article titles may be formatted like WebMD content but be indicated as "from our sponsor" (e.g., Monsanto). This could raise questions about the objectivity of the information, and, additionally, to what extent WebMD is collecting users' browsing data to tailor ads. In Chapter 4, I discussed how the presence of ads within WebMD's organizational information pages makes WebMD's commercial identity obvious and potentially less credible; in the context of the site's health information, when the goal is to locate objective information about a condition, the commercialism can be even more harmful to credibility.

A longer, largely text-based article on WebMD illustrates another mode in which WebMD presents medical information. The article “Understanding Parkinson’s Disease – the Basics” includes headings, bullet points, and hyperlinks, much like the NIH information. The hyperlinks seem less meant to define unfamiliar terms than to lead users to other, more general resources on WebMD’s site, such as its Depression Health Center. The article contains one image of a brain with the basal ganglia labeled and a close-up of a nerve cell. This illustration is used to help explain the cause of Parkinson’s: “Body movements are regulated by a portion of the brain called the basal ganglia, whose cells require a proper balance of two substances called dopamine and acetylcholine, both involved in the transmission of nerve impulses.” This article shows that WebMD’s information at times uses technical terminology and visuals, here in a more in-depth way compared to their Visual Guide.

Another unique feature of the textual information is the presence of a text-to-speech tool that reads the text aloud for users. This accessibility feature seems appropriate for medical information pages, where audience members may be experiencing impairments as a result of their condition. Users can simply highlight the text they want read or press a “Listen” button at the top of the article to hear the full text read aloud. Next to the “Listen” button are social media buttons with options to share the article to Facebook or Twitter. The NIH information pages have an option to print the document, but no sharing features, suggesting that WebMD information is expected to be treated in more social, interactive ways, while NIH information is expected to be treated more as a print document.

Another credibility feature of the articles is the option to view the article’s sources. Clicking on “View Article Sources” drops down a list of references, revealing

that WebMD has consulted familiar, credible sources in composing their information. Incomplete citation information, however, makes it difficult to trace back to the exact source. For instance, just the organization or journal is listed, such as *Journal of the American Medical Association*, rather than specific webpages, research article titles, or author names. In addition to peer-reviewed scientific sources, WebMD cites sources that are web-based, such as publications by the Parkinson's Disease Foundation. Such sources may be more focused on outreach for Parkinson's patients and fund-raising to support research initiatives. Unlike the NIH, which derives its information directly from clinical trials, WebMD draws information from more superficial sources in terms of scientific rigor.

In addition, each article has an expert reviewer listed, and a date of last review. The "Understanding Parkinson's Disease article" reads at the bottom, "Reviewed by Richard Senelick, MD on February 28, 2015." The Visual Guide likewise lists sources and a reviewer, "Arefa Cassoobhoy, MD, MPH," as well as a link to her biography describing her expertise in more depth. The sparse citation information in combination with the stamp of approval from a physician suggests that, when establishing the credibility of its information, WebMD appeals more to the authority of physicians than of scientific research. The date of review also emphasizes the value placed on currency; the "Understanding Parkinson's" article, for instance, had been reviewed only a few months prior.

Overall, in comparison to NIH medical information, WebMD's information is clearly more superficial; this is not necessarily problematic, since summary and breadth may be what a user needs rather than details and depth. WebMD even makes clear that accessibility and readability are the goal: Within each chapter, the articles listed are

accompanied by short summaries describing them as “brief,” “to the point,” and “easy-to-read.” The information is more engaging, visual, and usable than the NIH’s information. Though it lacks the depth of NIH information, its scope is broader in a sense. The inclusion of lifestyle and human-interest oriented material suggests that Parkinson’s patients are to be viewed as whole people, who are interested in more than just which treatments have been clinically proven to be most effective; they may also be interested in which celebrities share their diagnosis or how they will cope with daily issues like impaired driving skills.

The overview-like nature of the information, emphasis on accessibility, and explicit listing of medical doctors as expert reviewers show that this information is presented to users as though a doctor might explain a condition to a patient. The credibility of this information is connected to physician expertise.

PLM’s Parkinson’s Disease Condition Pages

Medical information on PLM is found on what are called “condition pages.” On the surface, the informational purpose of PLM’s condition pages does not seem so different from that of an article on a site like NIH.gov or WebMD. But because the condition pages are somewhat unusual in that their information is user-generated, this section begins with a brief explanation of them. The condition pages are meant to provide a visual summary of how other patients are experiencing and treating disease, so the pages contain visualizations of data that have been drawn from individual members’ profiles. In their individual profiles, PLM members track relevant medical statistics and qualitative measures such as their date of diagnosis, symptoms they are

experiencing, treatments[30] they are taking, side effects, and overall quality of life. As described in the literature review, this activity of quantified self-tracking is a popular e-patient behavior. What is perhaps less common is the public nature of the tracking on PLM, as well as the fact that PLM aggregates the data from individual user profiles into various reports for each condition. Therefore, from the main Parkinson's condition page, a user is no more than a few clicks away from an individual Parkinson's patient's profile.

This less conventional way of presenting information means that PLM has to do some additional rhetorical work to show the validity and usefulness of their data. At the top of the condition page, prior to the section of data displays, is a "Data for Good" advertisement (see Figure 19). This consists of a brief appeal for users to "donate their data." Explicitly, this section is an argument for users to enter their own data to enrich the PLM database; implicitly, this section is an argument about the quality of the data that makes up the information the user is about to encounter.

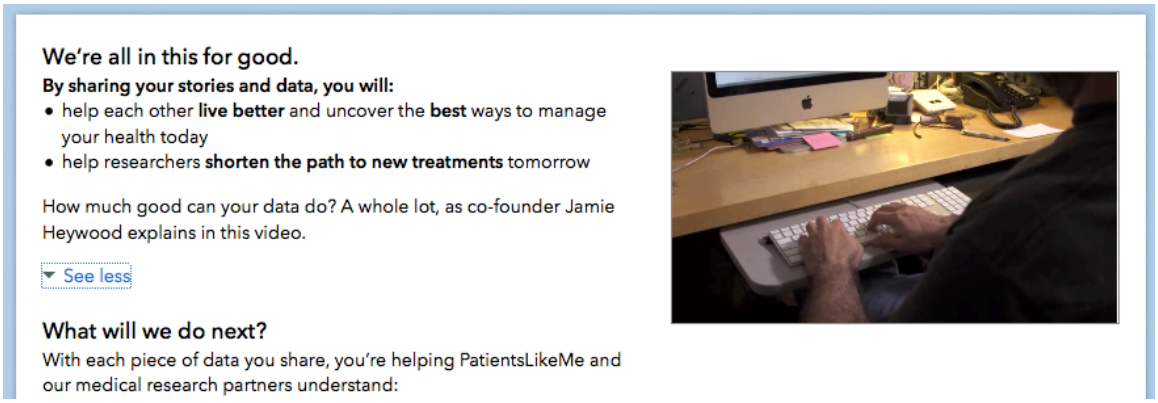


Figure 19: Data for Good ad on PLM Parkinson's condition page

[30] While prescription medications make up most of the treatment reports, interestingly, PLM also provides categories for less conventional treatments, even "pets" and "prayer." Inputting dosage and perceived effectiveness for something like prayer shows that PLM is quantifying even things that are widely perceived not to be quantifiable. At the same time, presenting reports for these broad options opens up perspectives that a patient might not hear of at a doctor visit.

Under the heading “You have already helped us learn” is a list of bullet points, one of which is, “Lithium carbonate wasn't helping ALS patients, and we learned it faster than the clinical trials did. Read about it in Nature.” This headline signals credibility in two ways. First, it highlights the currency of PLM’s data. Clinical trials are considered the gold standard for drug research (as the NIH.gov website emphasizes). Clinical trials are characterized by precise data collection procedures; PLM’s data is hardly precise in comparison. Yet, what PLM lacks in rigor, it makes up for in speed and currency, an especially persuasive appeal to patients with degenerative, terminal conditions. In addition, the *Nature* article addressing the PLM study is hyperlinked, approximating a citation by showing supporting evidence for the claim about lithium carbonate. It is a clear credibility move to highlight the fact that information gleaned from the PLM dataset is worthy of publication in a well-respected scientific journal. The full list of points, each with a link to a blog or other publication, is meant to demonstrate that user-provided data can be transformed into useful knowledge, while the phrasing “you have helped us” continues PLM’s rhetorical emphasis on patients as an active part of the learning process.

This central role of patients is also reflected in the patient video that accompanies the text of the Data for Good advertisement, in which Gus (pseudonym), a Parkinson’s patient, speaks at greater length about the benefits of the data he found on PLM. This feature stands out among the three e-health sites because it is the only site to include video. While video is not unusual for major medical websites or journals, this one is particularly powerful in that it represents the perspective of a single user. Furthermore, the choice of video as the mode of presentation underscores Gus’s humanness more than a paragraph of text would. He tells the story of his diagnosis, as

the camera follows him into his apartment and to his computer desk as he interacts with PLM:

> Believe me, I was shocked. I needed to talk to people who had the disease because only they knew what it was like and what I could expect, and could help me get through that initial shock. I went to the site and was amazed at the wealth of information that I found there, and the sense of community that was clearly evident from the first time I went on to the site.

Gus's video is folded into the larger Data for Good promotion – a charity drive of sorts for patients' medical data. The video ends on the Data for Good logo, which looks like a heart with three data points connected inside it. The slogan reads, "Donate your data: for you, for others, for good" (see Figure 20). The slogan appeals to altruism, essentially serving as a moral argument for patients to enter personal medical data into the PLM databases, not just because it is personally useful, but because it helps other people. The statement "we're all in this for good" reminds users of the community they can be a part of as well as of the fact that the community is in it for the right reasons – to help others. In other contexts where human data is collected on a large scale, the personhood and sincerity often seem stripped out, and this campaign places it at the center.

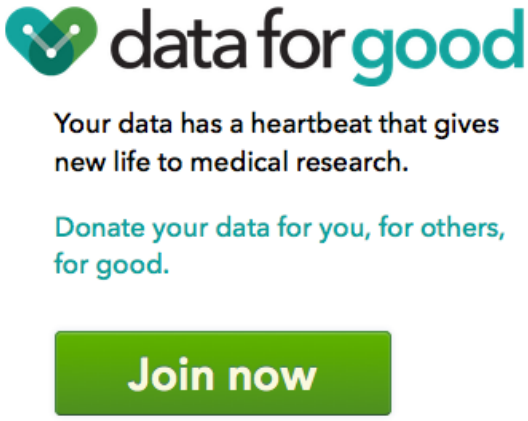


Figure 20: Data for Good logo

After the argument for the validity of the data, from both scientific and personal perspectives, the page then moves on to the actual information about Parkinson's. Interestingly, the definition of Parkinson's disease used on this page is exactly the same as the one found on PubMed health, but PLM does not cite it as a source. This may be an oversight or a deliberate rhetorical choice that assumes their audience may not find an NIH citation to be persuasive in this context. Then, the Parkinson's condition page is broken up into four major sections with data visualizations. The sections are labeled by question, such as "Who has PD[31] on PLM?" In answer to this question, five data displays – bar charts and pie charts – then summarize statistics such as age ranges, gender, age at first symptom, and type of Parkinson's. "Last updated: [today's date]" is indicated at the bottom of each one. The side effect and treatment reports had been updated within the past two weeks, further highlighting this information's currency.

Clicking into any of the bars or sections of the data displays will bring a user to the patient search page with that filter set. For instance, clicking on the pie section for

[31] "PD" is a common abbreviation for Parkinson's disease.

“female” will link to the female Parkinson’s patients. On the day that I was analyzing this part of the website, clicking on “female” led to the patients who had indicated they were male, and vice versa. A technical glitch like this poses problems with usability and, even if it is a solitary problem, can call into question the credibility of the information and the competence of the organization.

Another example of a data visualization is the “Compare treatments for Parkinson’s disease” section, which lists the top ten treatments that members use for Parkinson’s, and provides information about each in the form of bar charts that allow users to quickly compare both the perceived effectiveness and the severity of side effects for each drug. Figure 21 shows the top three treatments in the display. The charts use easily recognizable colors to represent major to slight effectiveness or severe to no side effects, and these colors are also indicated in a legend at the bottom.

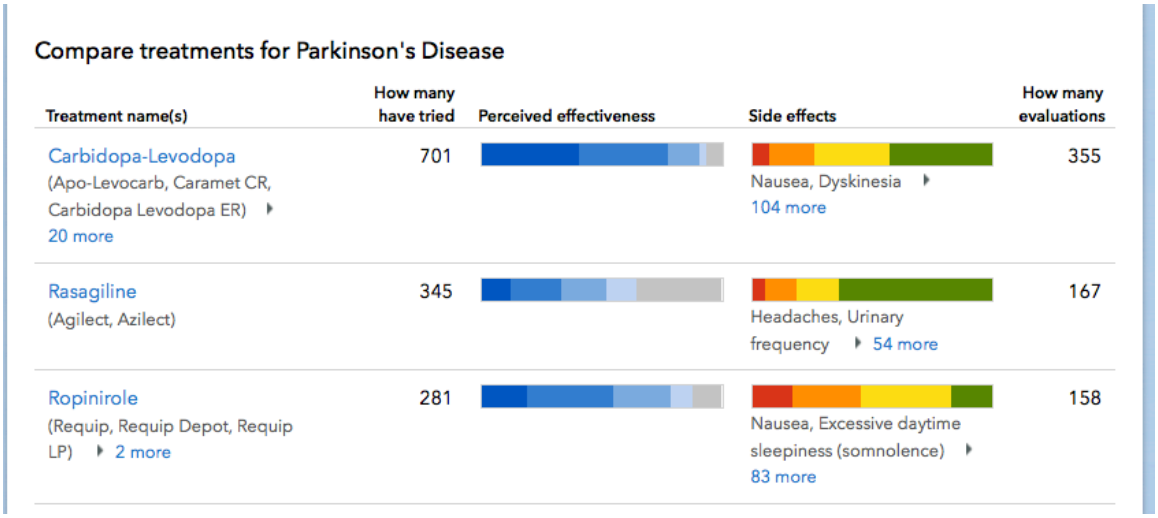


Figure 21: PLM "Compare treatments for Parkinson's" display

Except for the technical error with the gender pie chart, the data displays appear quite helpful and usable: According to generally accepted principles for effective data

displays, they use clear labeling and legends and are not over-complicated.[32] These charts convey an air of scientific precision, particularly when accompanied by statistics such as "9,105 patients have this condition." Likewise, the charts include scientific terminology such as "somnolence" (which PLM specifies is excessive daytime sleepiness) in the "What is it like?" section and "Carbidopa-Levodopa" (or the 20 other names the prescription medication goes by)[33] in the treatments section.

While charts, graphs, and figures are very common in biomedical literature, it is obvious that the data behind PLM's visualizations does not represent the kind of rigor and controlled data collection processes that characterize published clinical trials; the numbers on the PLM condition pages change at least daily, the population of PLM members is biased, and there is no control group. Nonetheless, this type of "automatic" or "casual" data collection and visualization may have its own kind of authority.[34] This is especially true given recent interest in big data and the persuasive sense of objectivity that comes from sheer numbers. While PLM's Parkinson's dataset does not technically count as "big," PLM advertises "25 million data points about disease" on its homepage. As with big data as a whole, on PLM there seems to be a shared belief in the ability of data to draw new insights from the messiness of reality. As Parkinson's patient Gus

[32] Using more than 2-3 categories with this "stacked percentage column" chart format can create too much visual noise (Skau, 2012). Therefore, PLM charts may not be readable for all readers. But, charts' *appearance* of being scientific, even when readers do not pay attention to the content, has been shown to be persuasive (Tal & Wansink, 2014).

[33] One way in which the treatment listing differs from that found on NIH.gov and WebMD is that it identifies brand names of drugs. This feature may be influenced by the company's business model, which involves selling de-identified, aggregated data to pharmaceutical companies.

[34] In an exploratory blog post, Shirky (2009) defines "algorithmic authority" as "the decision to regard as authoritative the unmanaged process of extracting value from diverse, untrustworthy sources, without any human standing beside the result saying 'Trust this because you trust me,'" as opposed to institutional or personal types of authority (para. 12).

says in the video, “It’s very, very helpful to share our stories and our data because it's the only way that we're gonna find a cure, and that's what we want.” It seems that the distinctive use of data displays on PLM builds on scientific credibility while also appealing to a newer form of crowd-based credibility.

As mentioned before, the interactive charts enable linking to relevant patient profiles. Not only does the hyperlinked nature of the condition pages make the experience very usable and relevant to the user, who can tailor their experience to exactly the information they want to zero in on,[35] but it also captures a lot of depth with one webpage as its starting point. For example, clicking on “slowness” within the “What is it like to have PD?” section leads to a symptom report, which opens with a brief description of the symptom: “A feeling of slowness of [sic] ‘bradykinesia’ is one of the cardinal symptoms of Parkinson's disease. People may have to concentrate very hard to carry out physical movements, or they may react more slowly to things going on in their environment.” This description has no citation, as though it is common knowledge. Nevertheless, the technical terminology serves as a textual credibility feature, showing PLM to align with the language of the medical system. At the same time, the definition contains a typo, which detracts from its overall sense of accuracy.

While this textual description, discussing a Parkinson’s patient’s experience in average terms, resembles the type of abstracted information found on NIH.gov and WebMD, the information following in the slowness symptom report is more individualized. From a pie chart broken down by the number of patients who have experienced slowness, a user can be brought to a list of other users experiencing the

[35] HCI research has found that customization or personalization has some positive effect on credibility in websites (Beldad, de Jong, & Steehouder, 2010).

symptom. The right column of the symptom report lists the patient icons of three of these patients, and also links to forum posts tagged specifically about slowness. It is clear that, like WebMD with its Parkinson's Community, PLM is trying to do more than just present information about slowness: It is trying to initiate interaction around this symptom on a community level as well as among similar individuals.

The patient search page enables users to filter a search by a number of variables such as age, gender, interests, and condition-specific features. In addition to screen names, the results page shows users' "nuggets," or a condition-specific visual summary of the member's medical profile (shown in the upper left corner of Figure 22). After searching, a user can then look more closely at any profiles of interest. Profiles indicate a patient's disease progression, treatments, and any other data the patient has entered. Figure 22 shows a sample patient profile, which includes statistics such as the patient's diagnosis date and PDRS rating (a means of quantifying Parkinson's progression) over time. This patient has three-star data quality (a measure of how thorough and up-to-date their profile data is).

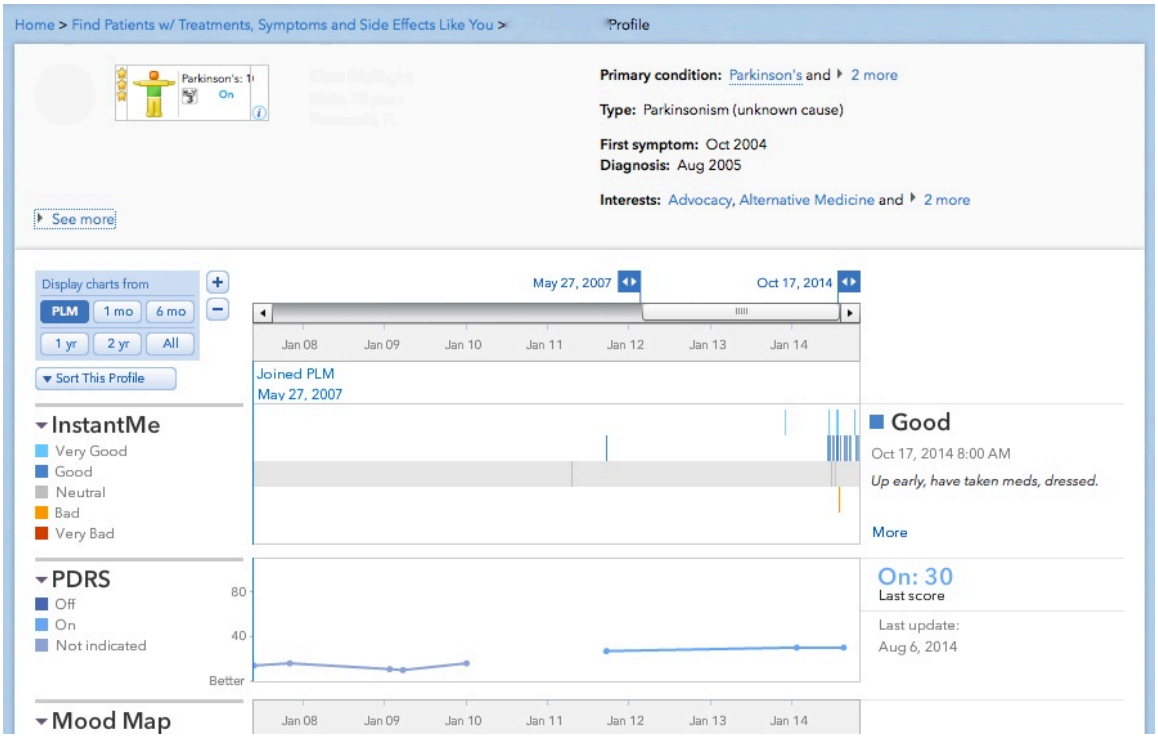


Figure 22: Public Parkinson's patient profile (identifying information obscured)

This search process is highly interactive and personalized. Users can choose which criteria matter to them. The profile search feature, linked from the data visualizations on the condition pages, allows users to see both the macro-picture as well as the micro-data that contributes to it. Credibility guidelines typically advise people to verify who the author of information is, as well as the author's credentials, qualifications, and expertise. That process is unrealistic for a large dataset like that found on PLM. Further complicating matters, PLM members are not required to use their true identities, and there is no way to verify the accuracy of the data they enter. Viewed another way, however, the ability of users to link to other user profiles serves as a form of quasi-citation that provides a degree of transparency and depth that users would not find from reading published clinical studies. The question of "where does this

data come from?" can be answered by drilling down to each individual data point featured on each individual profile.

The patient profiles enhance credibility because they serve as a way for users to verify authorship and expertise, albeit of an unconventional type. First, the timelines within the profiles enhance individuals' credibility and authenticity because presumably, it would be quite burdensome to deliberately input false information over time. Likewise, technical features such as the data quality rating give a clue as to the patient's level of commitment with keeping their data thorough and up-to-date. Second, and more importantly, the profiles serve as evidence of *patient* expertise: While most patients on PLM do not have medical degrees, their profiles provide evidence of careful record-keeping, of the ups and downs that characterize life with Parkinson's, and of a timeline of attempts to treat their symptoms. Users can also access others' reviews of medications, including qualitative descriptions, which provides a personal, individualized counterpart to abstracted lists of side effects.

In summary, as discussed in Chapter 4, part of what makes PLM's ethos so effective is that it is personal, and that carries through in its presentation of medical information. PLM shows that it understands that living with disease is different than simply having biomedical knowledge of a disease. As PLM co-founder Jamie Heywood says elsewhere in a Data for Good campaign advertisement, "Medicine doesn't really understand illness." That recognition holds a distinct kind of credibility among fellow disease sufferers, an experiential credibility of sorts. For instance, it is Gus's – a patient's – voice that is included prominently at the top of the condition page to help make a case for the value of the data; in addition, the theme of the individual in the context of a larger picture plays out very clearly in the condition pages, due to the

ability to toggle between the scientific data visualizations and the patient profiles contributing to the dataset. PLM sets up rhetorical arguments that take advantage of the public's increasing trust in large aggregated datasets and their potential to lead to new knowledge more quickly than traditional methods. Overall, PLM's credibility features reflect a balance of scientific and humanistic credibility which complement and overlap with each other. Credibility on the condition pages comes from more than just evidence and data; it comes from being part of a community with a shared purpose.

Conclusion

The previous chapter analyzed how each organization conveyed a credible ethos by drawing from different sources of authority: governmental/scientific in the case of NIH, professional/physician in the case of WebMD, or social/experiential in the case of PLM. In this chapter, an examination of the medical information put forth by each organization deepens our understanding of how these different sources of authority manifest concretely when each organization publishes information about a particular condition. A patient researching Parkinson's disease could come away from each website with the same general understanding of Parkinson's disease: who gets it, how it works in the body, and what symptoms and treatments are typical. But the information is presented differently and credibility operates differently in each case. For instance, though citation, writing style, page design, and use of visuals are deployed by all of the organizations as credibility features, how each feature signals credibility looks quite different from website to website.

Conventionally, a major aspect of source credibility assessment has been identifying the *source* of information and whether it is authoritative. Therefore, the different ways in which the websites cite others (with citation defined broadly) signal

how each organization constructs the authority of its information. While NIH cites studies in a formal academic manner, WebMD cites general sources along with a physician reviewer. PLM "cites" both a scientific study as well as individual users as the source of data, through hyperlinking to profiles. This reflects NIH's use of scientific authority, WebMD's use of physician authority, and PLM's use of peer or experiential authority to build the credibility of their information. These sources of authority are reflected in a sense of distance from the patient audience for each information page. On NIH, the science informs clinicians first and patients second; WebMD is structured as though doctors are informing patients; on PLM, patients inform each other.

Each website's information displays a different writing style and tone, with NIH using a more distanced, technical writing style, WebMD combining technical language with personal language, and PLM using primarily visual means including video to tell a patient's story. The pages also differ in interactivity, with the NIH's information being straightforward and largely text-based, WebMD's information providing some tools for personalization, and PLM providing ways to go deeper into patient data.

Each site has strengths and weaknesses in terms of its usability and readability, which maps onto credibility in at least two ways. First, if a site is well-organized and easy to navigate (as with WebMD's), it conveys the competence of the organization behind it. Conversely, broken links and grammatical errors (as with PLM) and poor organization (as with NIH.gov) can cause a user to question the legitimacy of the information. Second, if information is easy to comprehend, it can convey the author's goodwill towards their audience and desire to be seen as honest and transparent, as on WebMD. Conversely, jargon can make a reader feel distanced and ill-equipped to verify the legitimacy of the information, but can at the same time signal the author's

membership in a specialized, expert field, thereby establishing credibility in a different way. These aspects may be perceived differently and have a different effect depending on the audience.

Another important finding arising from this study is that even as sites move from informational to interactive, from expert to peer-based, appeals to the traditionally-respected authority of biomedical and scientific expertise endure. New visual and interactive forms adopt the "aura of objectivity" of scientific discourse – WebMD and PLM both use technical visuals and terminology, but then move in new directions by balancing the scientific and medical features with more humanistic, social, and crowd-based features. This pattern of more novel websites building on the familiar carries through from Chapter 4.

This comparison reveals that what counts as medical expertise looks different from website to website, and from community to community. To some, credibility can be reflected in data *and* stories. The more interactive sites, WebMD and PLM, best reflect the new social forms of credibility that e-health organizations are increasingly adopting to promote trust in their sites. To better understand these social, community-based ways that trust operates in e-health sites, I round out my three analysis chapters with a more focused look at a patient community and how peers build trust amongst themselves. Specifically, the next chapter examines the WebMD Community through an analysis of interaction within the Parkinson's discussion forums.

Chapter 6: Trust in an Online Patient Community

As Chapters 4 and 5 have shown, rhetorical features on e-health websites – in their organizational information pages and in the medical information itself – work to secure the trust of users. These rhetorical features take on different forms depending on the type of e-health website and the extent to which users are invited to participate. One of the main manifestations of the new social web is sharing among peers, which takes place in medical social networking sites and online medical support groups. When peers – lay people – interact with each other and with medical information, questions of trust become especially complicated. Trust is not only complicated, it is also foundational to the very existence of an online community, especially one like WebMD where the purpose is to seek and offer information. The exchange of information in a virtual community "is based upon the trust the members have in each other, and without this trust the virtual community there is no exchange and the virtual community will cease to exist" (Ridings et al., 2002, p. 288). This chapter examines interaction in the WebMD Parkinson's Community in order to better understand how trust operates in this context.

In online discussion forums, users are faced with a wide range of opinions, sources, experiences, and options to assess, all offered by people they likely have never met and for which there is no way to guarantee their identity. As discussed in the literature review, many scholars have been interested in how communication takes place online, given the different sorts of social cues available online versus face-to-face. Two major problems about trust and credibility that have been discussed in relation to medical discussion forums are medical misinformation and identity deception. Often these are intertwined; people can adopt a false identity specifically to gain access to

the community and promote spurious cures ("snake oil"). More likely, a poster[36] may be sincere but ignorant. At times, these problems are addressed with different forms of gatekeeping. In the WebMD Communities, that gatekeeping is in the form of experts as moderators. Still, WebMD acknowledges the limitations of largely user-driven communities, which they spell out clearly in a disclaimer on the WebMD Community front page (albeit in fine print):

> The opinions expressed in WebMD Communities are solely those of the User, who may or may not have medical or scientific training…WebMD understands that reading individual, real-life experiences can be a helpful resource, but it is never a substitute for professional medical advice, diagnosis, or treatment from a qualified health care provider.

Despite the concerns raised by online environments, people are still building relationships, disclosing very personal information, and finding value in the interaction and information disclosure taking place. So how do people navigate these trust concerns to form a viable community? Why do people trust their peers in addition to, or perhaps more than, the traditional authors of medical information – experts? As my previous two chapters showed, trust can be established in e-health sites by traditional rhetorical means such as the construction of a credible (and in some cases, distinctly expert) ethos. Even these strategies are novel considering that patients have only had such open access to medical information in recent times, and these strategies certainly also play a role in trust formation in online medical support communities. But, as work on social trust shows us, trust may be established in patient forums in more dynamic ways, in terms of how the *community* operates.

[36] By "poster" I mean a person who posts a comment to the discussion forum.

In this chapter, I first provide more detailed background on the forums: how they fit into the larger context of WebMD, how users access them, and how they are designed. These aspects influence who engages in the forums and how, so it is valuable to understand them before exploring the forums posts specifically. Then, I move to an analysis of a "time slice" (a year) of postings. Based on this time slice, I provide a "macro" picture of community activity to help set the context for how trust operates. Then, I examine specific communicative patterns or rhetorical dynamics that provide insight into how the community operates, and how these dynamics contribute to trust formation in the community.

Background on WebMD Communities

There are hundreds of WebMD Communities, which are asynchronous discussion forums. The main WebMD Community page (see Figure 23) breaks them down according to condition, groups of related conditions (e.g., cancer, diabetes, digestive disorders), or general topic areas (e.g., eating & diet, parenting).

Figure 23: WebMD Community homepage

There are many websites that provide forums for patients to discuss medical issues, but the things that make the WebMD Communities stand out are its connection to the well-known WebMD brand and the presence of expert moderators. WebMD hosts both expert-moderated communities and user-created communities. WebMD Communities are distinguishable from user-created communities by the "expert" tag (see Figure 24).

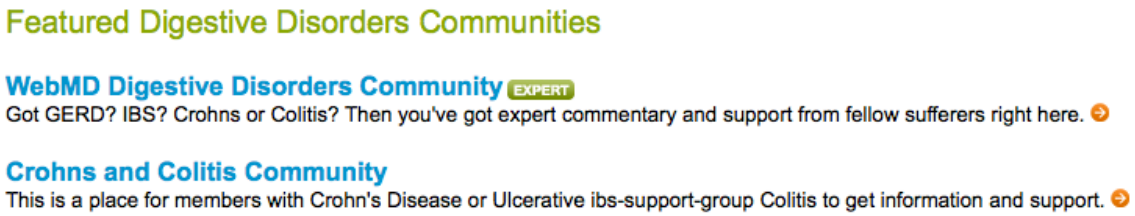


Figure 24: Example of expert-moderated and user-created communities

According to the FAQs, WebMD Communities are "moderated by WebMD and feature health professionals chosen by WebMD staff to provide reliable, credible, and

comprehensive information." Communities are fully publicly accessible, though user-created communities can be set as invitation-only, allowing more privacy.

WebMD is not as well known for its communities as for its informational articles; in fact, the communities are not even accessible from the WebMD homepage. Instead, they are linked to on the health information pages inside the site. Although anyone can browse the WebMD Communities without a login, they must register with WebMD to post. People also can make anonymous posts that are not connected with their profile. On their profile, users have the option to post a picture and a story. Based on the threads I looked at, it is rare for users to post an image of themselves or any image at all. The experts do have professional pictures and their full names and credentials on their profile. A user's latest posting activity is also recorded on their profile. Generally, a user's profile can be accessed by clicking on their screen name within the thread.

As with many online communities, WebMD has moderators and a set of policies to help govern interaction in the forums. The tasks of the WebMD moderators (who may be WebMD employees or experts) include welcoming new members, answering questions, informing users of WebMD content and tools, and "preserv[ing] the integrity and trust of the WebMD brand." They also help ensure that users are abiding by the Terms of Use, which prohibit users from posting content that is illegal, harassing, or for the purposes of advertising/soliciting. Overall, moderators and experts are present specifically to provide credible information and to promote trust in WebMD.

In the forums, members can post Discussions, Tips, or Resources. Tips and Resources can be rated on their helpfulness. In addition, users can add polls to their posts. The main page for a community lists the 30 most recently updated threads. Threads consist of an original post and any replies. On a community's main page, it

displays for each thread the poster's profile image and screen name, how long ago the comment was posted, and a preview of the text of the post (the full text of the original post can be read by clicking on a drop-down arrow). A thread where an expert has posted is labeled as CONTAINS EXPERT CONTENT.

Analysis of Forum Interaction

A Macro-View of a Year in the Parkinson's Community

Looking at approximately a year of forum postings makes it possible to summarize the activity in the WebMD Parkinson's Community. Posting activity is somewhat scattered and spread out, with approximately 107 total threads created over the course of a year (excluding duplicates). The number of responses on threads varied from 0 to 18, with an average of about 3 responses per thread. About 14% of threads were "orphans" (posts with no replies). There were 66 unique posters who began threads (not including the 20 anonymous posters), suggesting that many people come to the forum to get a question answered, rather than engaging with the community in a sustained way.

The topics that community members post about are constrained, in part, by WebMD. The community description sets the terms for who the group is for and what they might gain from the group:

> Tremors, stiff muscles, slow movement, balance problems. You've felt the frustrating symptoms of Parkinson's disease, and you know that it will get progressively worse. Whether you are striving to live your life with the disease or caring for a loved one who has it, this is the place to find information from top experts as well as understanding and comfort from others like you.

Based on the threads I studied, the number one reason people start a thread is to ask a question about their condition. Very few questions were off-topic; of those that were, many seemed aimed at generating discussion, such as asking about how people

have navigated a new healthcare system or how doctors ensure patient confidentiality. The majority of questions related specifically to Parkinson's and addressed issues such as diagnosis, symptoms, treatments, caregiving, and requests for support (and many of these topics overlapped in one posting).

- Questions about diagnosis. Examples: "I'm experiencing tremors that remind me of Parkinson's, but I'm not sure if that's what's going on. What do you think?" "My husband was diagnosed with Parkinson's, but his symptoms don't look like anything we've read about. Do you think the doctors could have gotten it wrong?"[37]
- Questions about symptoms and/or treatments. Examples: "I'm having skin issues. Do you think it's related to the Parkinson's?" "I'm experiencing swelling, I think from the meds. How have others dealt with this?" "What is the protocol for deciding which class of drug to start with?"
- Questions about caregiving for a Parkinson's patient. Examples: "I'm a teenager and my dad has Parkinson's. Any tips on how I can help him?" "I think my spouse is in denial about her Parkinson's. What can I do?"
- Requests for support. Examples: "I just found out I have PD and I'm so worried! Please help!"

Only 19 threads were started with the purpose of *sharing* information rather than *seeking* information, often a resource or a personal story that the poster thought would

[37] These examples are meant to represent the gist of comments, not comments in their entirety. As I explain in more detail later, in almost every case posters include additional information to contextualize their questions.

be helpful to the group. Examples are statements like “I just came across this Facebook page for Parkinson’s, thought I would share the link,” “I tried [supplement] and it has really improved my mood!” and “I lost thousands of dollars to this scam – don’t fall for it!” At other times, people post without a clear question but rather to introduce themselves to the group. Content analyses of online medical support group discussions (e.g., Mo & Coulson, 2008) have similarly found that informational and emotional support are the major activities in other support groups. The focus on symptom- and treatment-related questions in the WebMD Parkinson’s Community suggests that the main purpose of this forum is informational support. This informational purpose may be due to the presence of an expert moderator: People pose questions as though to their doctor. The questions are often quite individualized, and, as reflected in the examples of questions above, deal with serious and worrisome issues. Those who ask questions need more than just a sense of the character and credibility of the website; they need to be able to trust the responses, whether from the doctor or fellow posters.

This description of the basic functions and activity in the forum points to additional complications with trust. First, the fact that most posters are new or not repeat posters makes trust operate differently than in a community where most members post regularly, allowing them to develop knowledge of each other over time. Conversely, people who answer questions face different challenges. They may deploy particular strategies, or appeal to particular sources of expertise, to be seen as sincere and knowledgeable in their responses.

Second, the fact that most threads are started with a *medical question* suggests some additional challenges with trust. If a user is motivated to post a sensitive medical question online, it is safe to assume that they are in need of an answer, making the act

of posting a high-stakes event. It is in their interest to craft an initial post that conveys their sincerity and that helps others to take them seriously. The fact that most posters are new means they are likely to lack a thorough knowledge of community members and norms and may have to work harder to be taken seriously, as well as to decide which respondents to trust. As research on online communities has found, when new members post a question, "they will need to develop trust in a quick manner" (Talboom & Pierson, 2014, p. 90). This need is especially strong in a medical discussion forum where posting questions may be motivated by a time-sensitive concern.

The following (often overlapping) categories characterize patterns of interaction in the forums that relate to trust: medical expertise; a polite, supportive tone; identity and identification; disclosure; and experiential knowledge. In line with findings from other research on online communities (Ridings et al., 2002; Talboom & Pierson, 2014; Wang et al., 2008), these patterns are signs that the community is functioning effectively. I provide examples of each communicative pattern and explain how they serve as evidence that trust is operating in the forum. In addition, I suggest ways that these communicative acts contribute to more trust.[38]

Rhetorical Dynamics That Relate to Trust in the Parkinson's Community

Medical expertise

One of the most obvious contributors to trust in the group is the presence of the expert moderator, which aligns with WebMD's focus on professional, physician authority. The physician moderator can be seen as a gatekeeper, with the ability to correct misinformation as well as provide expert-based advice. Design features of the

[38] My goal is to show examples of communicative patterns in the forum related to trust; I recognize I cannot prove causality in terms of which acts lead to which effects.

forums help to build trust by prominently highlighting which threads contain expert content. Experts' contributions, and the experts themselves, are easy to identity. In the Parkinson's community, the resident expert was Dr. Jones (pseudonym). His profile image pictures him in a white coat and tie, and the medical institution he is affiliated with is included in the profile. WebMD has set up the forums and the doctor profiles to display the character and credibility of the doctor as a medical expert, and to align with WebMD's overall ethos as a professional, expert website.[39] These features extend the expertise-based credibility strategies discussed in the previous two analysis chapters. However, trust is built with the physician in more complex, individualized ways because of the interactivity of the discussion forum.

Overall, the discussions reflect a sense of trust in the input of medical professionals. One sign of users' respect and trust in medical authority comes from the fact that they often reference their doctors' recommendations or advice, possibly to lend credibility to their own comments. When A posted a question about dealing with anxiety, B responded by situating her advice in the context of a recent conversation with her doctor:

> I had an appt last week with my Neuro and we discussed the increasing anxiety and trouble sleeping. I was started on Celexa… He told me it would take about 2 weeks to really notice a difference… I have discussed this with other caregivers and they concur that this is more common than we think in Parkinson's.

And when C expressed worry about her recent diagnosis of Parkinson's, D shared her experience of crying every day from the time she was first diagnosed, and the advice her doctor gave her:

[39]The status of the physician as the official expert moderator is further enforced by WebMD's policy that users not include professional titles in their screen names to avoid confusion.

> My neuro wanted me to see a therapist then and the therapist helped me come to come to terms with having a progressive disease… My first neuro told me something that I always like to remember. She said you can either die with pd or live with pd. I chose to live with pd.

There are also several indicators of group members' gratitude and appreciation for Dr. Jones, who was at one point referred to as "our knowledgeable friend Dr. Jones." For example, several posters directly addressed him with their questions ("Dr. Jones could you weigh in?") and they addressed him politely and respectfully. One poster opened her comment with "Hi Dr. Jones, Hope everything is well with you," and posed a question about the possible cause of the jerking motion she was experiencing. She closed her comment with, "As always, thank you for your help Dr. Jones. It is so great that we have the opportunity to come to this website and be heard!!!!! You are appreciated!!!" Dr. Jones answered the question and said that everyone on the site wants what is best for her. The original poster responded with, "Thank you Dr. Jones. You are too funny. I feel much better now and will not worry about those minor jerks!!! Yes, it always seems to be at the end of the day when it jerks. I swear since I have gottent [sic] PD I make mountains out of molehills." The fact that the poster felt reassured by the advice suggests that she trusted him.

Another poster ended her comment to Dr. Jones with "Thank You for all that you do for Parkinson's," showing gratitude not just for an answer to a specific question but for his contributions to healthcare as a whole. In a different thread, E was looking for resources to help her father with Parkinson's. F suggested that E recommend the Parkinson's community to her father, explaining that "Dr. Jones is great and usually answers questions within 7 days." For F, then, part of what made the group so valuable was Dr. Jones' relevant and prompt replies. Other members followed up by expressing

not just thanks but also their intentions to take the doctor's advice (which, often, was to talk to their own doctors).

During the timeframe studied, the physician moderator dropped out of the group with no warning. The way posters responded to this provides further insight into the value they placed on the physician perspective. After a stretch of time with no input from the physician, members began to speculate about his absence, wondering if he was on vacation. Some people posted comments like "Dr. Jones I hope your vacation is about over" or "Dr. Jones where are you? I hope you read this."

At one point, a regular poster, G, started a thread in which she concluded that they were "on their own." H replied, "Yes, it has been quite a while! I hope we aren't flying solo much longer!" Someone speculated that there were budget cuts or that the doctor was out to learn of new research to bring back to the group. They started making plans to contact him at his medical institution, showing that they considered their relationship with him to go deeper than the context of WebMD itself. G wrote,

> I have Come to the conclusion Dr Jones no longer part of WebMd. I also have concluded that this site is no longer monitored. I also believe [they] would have said good by if they could have. I have been contemplating sending email to Dr Jones at [hospital]. What do you think? Would this be unacceptable?

H replied,

> I tend to agree with you about this site no longer being monitored, which really ticks me off. I feel like WebMD has left all of us hanging out to dry. I would think trying to contact Dr. Jones at [hospital] would be reasonable since we have tried all other methods suggested by this site.

Another considered it "false advertising" that WebMD had not taken down the expert label on the group.

Once the community established that they were "on their own," they spoke of their responsibility as a group to help each other out. According to H, "let's keep on

posting and helping each other the best we can!" It seems that a core group stepped up with advice giving. H, who identified as a retired registered nurse, took on some of the burden of answering medical questions. She concluded one reply with, "BTW, I am a Registered Nurse so I have had experience helping women with this problem. I am also noticing the same problem every once in a while," drawing on both professional and personal experience to build the credibility of her statement.

S, a caregiver, asked a question about her father's issues with swallowing. H, the registered nurse, responded by saying it was a common problem and sharing her suggestion of a soft diet. S thanked H and said she would pass on the "good" advice to her father, demonstrating that she valued it and planned to act on it in some way. H replied, "Glad I was able to give good information. I'm rather disappointed with this community... not all of us PD patients and caregivers, but the apparent loss of our resident 'Expert moderator.'"

In another case, J asked a question about treatments. G referred J to H, saying, "H maybe you can answer the question on medication for bladder control. Medications are out of my realm of knowledge being a nurse you may be able to answer her question." These exchanges suggest the value placed on medical knowledge. Though the group expressed that the physician's expertise was greatly needed in the forum, in the meantime, someone else came to be seen as a trusted advice-giver on the basis of her medical credentials and of her history of helpful contributions.

Polite, supportive tone

One pattern that characterized almost all of the interaction in the Parkinson's community was the use of politeness. There were strategies people used to show a perfunctory level of politeness (such as statements of greeting and thanks). Walther and

Bunz (2005, p. 842) found in distance work teams that “saying hi matters”; in their study, greetings correlated with an overall better functioning, high-trust community. Greetings were common in the WebMD Community as well; examples include “Hey everyone!” “Hi there,” or “Hope all is well.” In the community, many posters also included closings such as “God Bless,” “thx for any info,” or the unusually formal “Your consideration of this question is important and appreciated.” The physician’s responses, too, often expressed a sympathetic and supportive (though more formal) tone, such as “I am sorry to read of your difficult time.” The politeness and caring expressed by the physician may have influenced others’ trust in him, perhaps more than or in addition to his expert credentials.

These basic politeness strategies help to smooth interaction and set an overall tone of civility in the forum, creating a safer space for communicating. Numerous scholars, many of them drawing from Brown and Levinson’s (1987) classic work on politeness theory, have observed how politeness contributes to social harmony (Culpeper, 1996) and how politeness is especially important for successful electronic interaction due to the absence of nonverbal cues such as facial expressions and intonation (Graham, 2007; Walther & Bunz, 2005). Saying “hello,” “thank you,” and “sorry” may seem like insignificant or basic norms, but in the WebMD Parkinson’s Community, where people do not know each other, and where trust needs to thrive in order for people to give and get helpful health advice, politeness seems to serve a very important function.

There were also ways in which posters went a step further with politeness strategies and expressions of goodwill. For instance, closings were an opportunity to go beyond pleasantries and start to establish relationship with another individual:

- "Please let us know how you're doing once you've talked to your doctor."
- "I wish you many more good days and the warmth of sun on your face."
- "I send you many caring thoughts and hope that you are doing well."
- "Good luck, and I'll keep you and your husband in my prayers."

These comments show care and a desire to extend interaction beyond just a short information exchange.

Another politeness strategy used was to qualify or "apologize" for questions that may be burdensome, confusing, or reflect ignorance. Prefacing questions with statements like "I know this is a stupid question, but," or "please forgive my asking so many questions," work to present someone as humble and respectful of others' limited time and greater knowledge. One poster expresses great surprise at having received a response at all, writing,

> First off, I would like to extent [sic] my sincere thanks to Dr. Jones, K and G for replying to my post!!!!!!! I was so shocked that someone actually took the time to write bacl [sic]!...Thanks to you folks for making my day a little easier to get through, bless you for your courage and willingness to help a stranger.....!

H responded, "I have learned so much from this community...I know you will, too. We are always here for each other!" Such exchanges build relationship, reflect the supportiveness of the group as a whole, and indicate that people trust each other enough as information sources that they value what others have taught them.

Yet another way that community is built is through the use of extraneous details, humor, and stories, which suggests an attempt at revealing the person behind the comment. Humor may be used to bring lightness to a serious situation ("I've had so many scans I should glow in the dark"), and extraneous details, unrelated to

Parkinson's, may be used in the context of a Parkinson's discussion to move an interaction to a more personal level: "Grandkids have been up here from [place] and had them last weekend. They are 14 and 12. We went from winter right into a rainy hot summer."

One particular thread exemplifies the use of stories and humor. The thread was the longest among all the threads analyzed. It started out with a question regarding meningitis and weakness, but ended up as a dialogue, peppered with smiley face emoticons, between two posters sharing stories and well wishes. G joked about a dream in which she ran a marathon using a walker. H built on that, saying "I see a woman running with her walker, complete with tennis balls on the back legs of the walker and a bike horn attached!" Another interesting moment in this exchange was when G pointed H to another thread because G felt her response was insufficient: "I am not the most tactful person and my response may have been a little on the cold side. Could you take a look and respond." This suggests a sense of responsibility for responding appropriately and helpfully not just to recognized members but to "newbies" as well.

The very relational, somewhat off-topic exchanges were not as common throughout the threads I analyzed, and this makes sense given that the Parkinson's community is primarily an informational board. Nevertheless, the community norm of civility and care became especially pronounced when someone violated it. In one thread, a user posted a comment that was later deleted, but others' responses to it show that it was clearly insulting and inaccurate. The responses are very out of the norm in terms of tone, as posters expressed great anger and called this person "a nut case," told them to "get a life, but somewhere else," and to "crawl back in their cave."

Someone threatened to report them to WebMD. Members described this person's comment as "unfounded remarks," a "line of BS," an "ignorant crock of s," "ridiculous," and a "load of phooey." One poster asked, "just WHAT is your so called knowledge based on?" and advised the person to "Get acquainted with several GOOD PD websites and stay off the blogs. Too many people have their own agenda and give crackpot advice. Start with some recommended by your doctor." Other critiques reflected the insensitivity of the comment:

- "You dare to make those statements to a community of people with Parkinson's who deal with this diease [sic] everyday."
- "Wehave [sic] a neurological disease with no cure. Do yourself a favor and study, exercise and yes... pray."
- "This site is for those of us who have a true concern about helping each other with our condition."
- "We have a serious disease t.hat [sic] has to be delt [sic] with by professionals, supported by physical therapy and a strong belief in God."

These comments all reveal a self-policing process and a sense of protectiveness towards the group. Members had no tolerance for blatant misinformation, nor for the lack of sensitivity to them as a vulnerable group. At moments like this when someone enters the community and blatantly violates community norms, it can lead community members to articulate their standards, the purpose of their community, and who makes a legitimate member. Graham (2007) noted a similar dynamic in a church-based e-mail group, in which members attacked another member for responding rudely to another's emotional disclosure. She noted that this conflict brought group norms into relief,

seemed to ultimately enhance rapport, and provided an opportunity for the group to clarify its identity.

In this particular WebMD exchange, the conflict brought to the surface the value that members place on politeness and sensitivity, as well as an understanding that legitimate members have sincere motives, a "true concern" for helping each other. It seems that trust is built through sincerity of motives and a shared identity as a person with Parkinson's or a caregiver of a person with Parkinson's. Research has shown that people with similar backgrounds or health experiences show more empathy towards each other; a sense of support within a community influences users' perceptions of the credibility of advice they receive in that community (Wang et al., 2008).

This sense of protectiveness and use of an atypical angry tone also came through in a thread where a poster attempted to warn others away from a scam that they had fallen prey to. O writes, "Against the wishes from my RA & PC docs, who thought it was one of many ways to take advantage of chronic pain sufferers, I bit the hook of the promises of [Clinic]. Desperate people in pain tend to do desperate things." O's post was quite long and detailed, including specific dosages of the treatment in question, what the poster paid for it, and the negative results. The angry tone towards the company was balanced with words of understanding towards other posters whom O wished to warn: "I hope this helps others from being preyed upon. When one is in pain, one tends to try everything and everything to help relieve our symptoms." O added that "I have seen some of their solicitation replies to people posting their symptoms on message boards so be aware," highlighting the potential dangers of participation on message boards.

The first respondent, P, replied, “I am so glad to find this. I talked to [Clinic] today and they want me to sign up tomorrow. What is the rush? I need to talk to my doctor and others in the health alternative field I trust before taking a drug that is well known to be problematic.” While P did not explicitly state that they trusted O, it is clear O’s post was credible enough to P that he/she planned to do more research before trying the therapy. This example shows how information exchange in a forum (and a detailed narrative of personal experience) can intervene in users’ medical decision-making processes.

Other participants in the thread came to ask more questions and to share results of their internet research of the clinic and the many complaints that had been filed. One person said, “Check out the credentials of the Doctor involved.” It came to light that the person running the clinic was not a medical doctor but a retired university professor. Interestingly, another poster came along representing the clinic in question. They stated they are A-rated by the BBB and restated statistics about symptom improvement according to two studies. This defensive post represents an attempt at reaffirming credibility that has been called into question; strategies included citing statistics, mentioning credible organizations such as the FDA, and distanced, scientific language, e.g., “Success depends on quality patient education, dosage customization, administration timing and patient compliance. Participating physicians report no significant side effects.”

Not surprisingly, this abstract, deflecting response was not taken well; the original poster, O, rebutted the points in long, angry replies, calling it a “bunch of baloney” and saying of the doctor behind the scam, “He is not, not, not concerned about your health!” O contrasted their own motive as “from the heart” against the

company's motive to "protect their flow of money." This thread illustrates how unethical organizations may attempt to adopt the credibility features of trusted organizations and information and affirms one of the major dangers and complications of trust online, especially when people are desperate for a cure or for relief. At the same time, it shows how online community can work as a warning system and help others become more critical of claims.

Identity and identification[40]

A recurrent pattern in postings was for posters to situate themselves in relationship to Parkinson's disease and/or the online community. While there were at times standalone, abstract questions with no reference to the poster of the question, such as "Are swollen ankles common with Parkinson's?", the standard way of introducing one's question was to provide some background. Comments like "I'm new to this," "I normally lurk," "I haven't posted in a while," or "I've written in the past," help other posters understand the person's history and relationship to the group.

More frequent than that, though, is the move of providing background related to their disease. Many people opened their posts with background such as "I am 44 and have…," "my father is 60 years old and was just diagnosed…I'm an EMT but I have never been around this disease before," or "I am 64 and otherwise in good health, but I think I may have Parkinson's," suggesting a standard way of positioning themselves in terms of their age and history with the disease. Other researchers describe how, by

[40] While Kenneth Burke's identification is probably at work here, I am not using these terms in a strict Burkean sense. By "identification" I simply mean the moves people make to point out their similarities in relation to each other or the community.

sharing details like age, gender, and personal problems, users become “less of a stranger” to each other and move towards friendship (Ridings et al., 2002).

Many go on to carefully describe details about their medications (often with exact dosages and times taken), symptoms, and doctor visits. In a couple of cases, posters even used numbered lists or headings to break up their health history. A study of an online review community suggests that features such as depth, details, and even usability features (such as formatting) in comments are a means of gaining trust (Mackiewicz, 2010) and this may be the case in medical communities as well.

Of course, the intent behind including such details may be to elicit more relevant responses rather than to come across as more credible per se. But such introductions may still serve to build trust because they help other members get a feel for who is participating in their community and why. Background information that clearly situates the poster in relation to Parkinson’s disease, followed with an on-point question, helps to show the poster’s conformance with group expectations. Strange or off-topic requests may be ignored or questioned. For example, a poster claiming to be a student in biomedical engineering stated that he/she would like to research in the Parkinson’s field and “could you please help me.” The lone respondent says “your question for research begs for more information I'm not clear on what it is that you need from those of us who have Parkinson's.” There are many other reasons a post may not receive a response, but this short exchange is one example of what can happen when a post falls outside of what is expected for the group in terms of purpose and identity.

While the posting of a personal question, in and of itself, indicates that poster’s step of trust in the community, respondents almost always reciprocate, identifying areas of commonality with the original poster, creating opportunities for more

disclosure and more trust. Typical statements of identification included “the problem with swallowing food/drink is not rare with Parkinson's. I have it as well and understand the concerns that you have,” “I too have had difficulties with the medications that were given me over the years that rival the PD symptoms,” or “Man, I’m with you!” Sometimes posters point out other areas of commonality unrelated to the disease, e.g., “Hi Barb, I’m a Barb too.”

At times, the identification is more emotional than physical, especially in relation to caregivers’ concerns: “I am where you are, after a year, my husband told me he has Parkinson, I am in shock." Another poster responded to a caregiver by providing his/her own, similar story:

> Hi, I feel your fear and confusion. I had to take over my mother's life because of [Alzheimer’s] and it is really scary to get into another person's personal business and discuss things that have an impact and possibly chance [sic] her life and lifestyle.

There are also more generic statements that reassure users that they are not alone in their situation: “I'm sorry to read your discussion, but I am responding to you mainly because I wanted to tell you that you are NOT alone with your medication problems,” or “You are not alone out there.” One poster, T, used the language of “this journey we are on” to describe the shared experience of having Parkinson’s.

Another strategy that signaled trust and that may have further built trust in the community was when users affirmed others, whether in agreement with a specific statement (“G has definitely given advice that is true,” “the advice given is right on target”) or in a comment about the value of someone’s contributions as a whole (“i reflect on you …. and some of the other people who have given so much on this board…,” “you've always been a terrific source of accurate and helpful info”). In one

thread, the physician moderator did not respond right away to a medical question, and others stepped in to answer. He validated their history of contributions, saying “Thank you A and B, for your, as always, caring and helpful advice.” Others reading the thread might then be encouraged to trust in A and B because of this recommendation by a trusted source, a physician. Such knowledge of other posters as valuable contributors can only be developed over time. As Sztompka says, “Being visibly trusted by some may be an argument for others to grant trust too” (as cited in Talboom & Pierson, 2014, p. 94). Social validation is the old-fashioned recommender system: Expressing validation of others’ expertise and the validity of their input helps build trust in particular members and types of contributions.

Disclosure

Another means of trust-building, closely related to the previous two categories, is disclosure (Henderson & Gilding, 2004; Ridings et al., 2002; Talboom & Pierson, 2014). The very nature of the Parkinson’s community as a support group for a chronic, degenerative condition makes it natural that users will share sensitive medical details with each other. However, there were moments where users went beyond sharing medical details and reached out to others in more personal ways. One small example of this is the use of signatures. With the exception of two screen names which contained a full name, all screen names were non-identifying (often something like “pdmom50”). But, in several places, brand new as well as more regular posters would sign their name (usually a first name), which represents a greater level of disclosure of their identity than their screen name alone. In one thread about an unfortunate side effect a poster experienced, he did not sign his name the first time he posted, but after receiving supportive responses (one of which was from another poster who signed her name), he

began to sign his name to his comments. There are many reasons people might sign their name, but it could indicate an effort at reaching out or that people felt safe enough not to "hide" behind a pseudonym.

While most screen names were pseudonyms, in that they did not link the poster to their in-person identity, posting under a consistent screen name still enables an individual to develop an identity within the context of the forum, and this reputation is a source of online trust (Henderson & Gilding, 2004). Therefore, the fact that WebMD enables an anonymous posting option is interesting in terms of how it may influence trust in the community. Completely anonymous postings lack the identity cues found in a profile and the history affiliated with a screen name. While I was unable to identify any particular rhetorical patterns in anonymous posts or responses, I did observe that, on average, threads begun by anonymous posters received fewer responses per thread than those begun by posters using screen names (2 vs. 3). There could be a number of reasons for this, and I cannot make any claims to statistical significance, but I do think it raises questions about the relationship between identity and trust. Responsiveness to posts is a sign of trust in a forum (Ridings et al., 2002), so this difference in responsiveness could point to the importance of disclosing even minor aspects of identity for trust-building.[41]

Another example of the exchange of personal information took place during the time when users were wondering about the absence of the physician moderator. One theory put forth was that the whole site was shutting down and people started

[41] On the other hand, posting anonymously, especially when talking about sensitive health or personal issues, can create a sense of safety for a user, knowing that their details will not be linked to their offline selves. Perhaps WebMD intended to offer the option of more privacy given the very public nature of the forum. Future study of the advantages and disadvantages of anonymity, "pseudonymity," and real identities in health forums would be valuable.

discussing the sharing of contact information so they could maintain their relationships. One person commented, “I really have gotten a lot of support from everyone that posts. There are a few of you I would especially miss.” Two members shared their locations and discussed the possibility of “networking” in person. At a later date, when it became clear that the doctor was not just on vacation, a poster shared that she was still willing to offer her e-mail address to Parkinson’s patients. “I wish there was a way to give you my email address without the whole world seeing on this stie [sic]!” she commented, then posted it anyway, adding “I can always change it if I start getting wierdos [sic].” This reflects a recognition of the vulnerability of communicating in a completely open space, yet that for this member, the benefit of staying in touch outweighed the risk of her contact information being misused.

While this thread alone does not tell me whether members met in person or started communicating in another medium, a different thread showed evidence that members had communicated via e-mail (“check your e-mail”). These moments where members reciprocally share personally identifying information and make plans to take their relationship outside the context of the forum is a sign of trust between members; this “media switching” is a “signifier of trust (I trust you enough to give you my phone number), but also a way in which identities can be established,” thus contributing to more trust (Whitty & Joinson, 2008, p. 101).

Besides the sharing of contact information, trust seems to be built through emotional disclosure. Expressing emotion in a public forum indicates the vulnerability that one takes on in order to receive support. Accordingly, it seems that these posters have trusted strangers to treat their disclosure with sensitivity. Examples of emotional disclosure that accompanied a question include:

- “I’m so worried”
- “I feel alone”
- “This is so stressful”
- “I don’t understand this disease and I’m just lost right now”
- “I’m at my wit’s end”
- “I’m scared and looking for direction”

These comments may also alert readers that the poster needs a prompt and compassionate response. These feelings are legitimate ones when dealing with a new diagnosis or a stressful situation, and in many cases readers reciprocated the disclosure in statements of identification with the poster to provide support. For example, V expressed that she was struggling to come to terms with her new diagnosis. T responded by sharing her successful experience treating Parkinson’s along with supportive comments. V said, “You are very encouraging,” and proceeded to share more details about her situation. This exchange suggests the development of trust between these individuals, likely aided by their common plight as Parkinson’s patients. An interview study of internet users found a similar cycle of reciprocal disclosure: “Respondents consistently emphasized the role of self-disclosure, whereby trustees purposefully changed the context of their own actions by disclosing something personal. This encouraged the other person in the exchange to say something personal, and on it went” (Henderson & Gilding, 2004, p. 501).

Experiential knowledge

I have talked about how the presence of a trusted overseer with medical expertise works to create a sense of safety and trust in the community. However, expert knowledge is not the only type of knowledge that is valued in the community –

personal experience is also valued. Expressions of experiential knowledge often coincided with identification moves, showing how advice-givers highlight their similarity of experience to better persuade others of the applicability of their advice.[42] The group's trust in experiential knowledge is shown in the fact that many people who post a question specifically ask for the advice of others who have had a similar experience ("Anyone else have this experience?" "Does anyone else have this problem?"). People sought others like them, not only to get advice but to know they were not alone.

Some statements directly expressed the value of experience in understanding the disease and having knowledge of it, for example:

- "No one knows except someone else with PD. I could go on and on, but I won't."
- "most of us have faced different aspects of this disease and as a whole, we are a wealth of knowledge! (as long as we can remember !)"
- "There is lot's of medical information on the general WebMD site, but if you want to find out from those of us already in the trenches, read everything you can."

An example of how personal experience contributes to trust in medical advice is when T posted the story of how his/her Parkinson's symptoms improved from taking a specific alternative supplement: "I take 4 a day and I feel 'giddy' and have that 'good mood feeling'! I highly recommend it." The first respondent, U, described some of the

[42] This finding aligns with many other studies that have observed the power of personal experience, and especially similar experience, in building trust. Wang, Walther, Pingree and Hawkins (2008) found a strong connection between homophily (similarity) and users' likelihood to act on health advice in a forum, leading them to assert that "homophily is really the factor that grounds credibility and drives the whole persuasive process in the context of online health information" (p. 365).

problems his/her brother was facing as a result of Parkinson's and asked for more information about the supplement. G, a regular poster, responded to U to explain that the supplement is a natural source of levodopa (the standard medication for treating Parkinson's). G advised, "it sounds as if your brother has not recieved [sic] any medical care. He needs to see a neurologist so he can get on the right regiment of medications." While T's testimonial was not misinformation per se, it did present the supplement as a miracle cure, and U seemed prepared to trust it based only on a stranger's personal experience. G's response guiding U to seek a doctor's advice could be seen as her efforts to protect someone who may be taken in. Rather than acknowledging the suggestion of a doctor's appointment, U responded again with "tell me where I can buy [supplement]." This exchange illustrates the power of personal experience to lead to trust in claims, perhaps to a harmful extent. At the same time, the thread illustrates how other community members may contribute contrasting or additional advice to help ensure that multiple perspectives are voiced.

Another sign that experiential knowledge is valued is that posters often legitimize their advice-giving on the basis of their diagnosis status or experience as caregivers. One way in which this played out was in responses to caregivers. People with Parkinson's were able to weigh in on caregivers' situations and help them understand what the experience of disease may be like for their loved one. These threads were opportunities for group members to educate others who lack the first-person perspective but need it in order to relate successfully with their loved one. For example, G advised a caregiver, "Above alll [sic] NEVER show pity. We know our brain is slowly being destroyed." This "we" language suggests a perspective based in personal experience. At other times, advice-givers explicitly mentioned the type of

experience that authorized them to offer input. L posted a question about her mother's decision to end treatment. M said, "I hesitate to respond. I know you asked for a care taker response but I am going to respond as I have PD" and N said, "I can respond as both a pd patient AND a retired RN Case Manager." In a different thread, in which a caregiver was asking about hospice care, N prefaced her comment with even more detailed indicators of expertise: "Let me sort of advise you based on my former nursing career of over 30 years. The last 15 or so was pretty much exclusively Geriatrics/Dementia, which of course meant there was quite a bit of preparing for death." Even when a caregiver did not explicitly ask for the perspective of a Parkinson's patient, respondents found that their patient experience enabled them to offer helpful insights, in the latter case, combined with professional experience. At several points, respondents would qualify their advice by explaining how Parkinson's is different for everyone.

Other threads help illustrate how community members understand the limits of their advice and who is authorized to give certain types of advice. A comment such as "I think this is a Dr. Jones question" implies that some members recognize what types of questions may be better answered by a professional than by a patient. The physician moderator, too, very often told people to check with their own doctor. One concrete type of advice that members were able to give based on their experience was help in navigating the medical system. If someone expressed that their doctor was unable to help them, some of the advice came in the form of how to identify the right kind of doctor, e.g., "Contact your Neuro. A GP is not the right person to ask. Your doctor needs to be a Neuro who specializes [sic] in Parkinson's or movement disorders."

In one case, Q posted a question about whether they may have Parkinson's based on some symptoms he/she had observed. The first respondent, R, explained their background with the diagnosis, how long she had had it, and the treatment she found helpful (deep brain stimulation). Q wrote back, "Thank you for your help. I will mention deep brain stimulation when I meet with a neurologist .I am happy to have found this site," showing that R's testimonial was trustworthy enough to lead Q to further investigation of the treatment.

Another situation displayed how members found experiential knowledge trustworthy enough to act on. A question about bladder problems invited responses from others who had experienced it; all of the respondents offered practical advice in terms of what had worked for them. The original poster as well as another poster expressed gratitude for the suggestions as well as intentions to act on it, e.g., "Thank you, I will start drinking more fluids."

Conclusion

This analysis aligns with what we already know from other studies about how trust operates in online communities. Disclosure, support, and identifying with others are all important rhetorical dynamics in this community. These patterns not only characterize interaction in the community, they also serve as evidence that trust is operating. New members post personal questions, indicating a sense of trust in the community at the outset. But my analysis also suggests that when a poster's disclosure of personal experience is reciprocated, through identification, and in a supportive and polite tone, trust is further established. In terms of disclosure, one thing that is specific to trust-building in a health-focused support group like the WebMD Parkinson's Community is the sharing of very technical and precise details about individuals'

treatments, dosages, and diagnosis history. Invoking the shared plight of having a degenerative illness is another thing one would not find in online communities of a different nature. There is evidence in the forums of relationships forming over time (even moving beyond the context of the forum), as well as support and connection even among complete strangers.

A strong finding is the centrality of identification, combined with experiential knowledge, as an apparently trusted source of authority for advice-giving in the forum. While this finding matches findings from similar studies, it is particularly interesting in WebMD given that this is a moderated forum. One of the reasons users may come here is for expert, vetted advice from a physician (and indeed, many requested exactly that). Still, many members request advice specifically from others who have gone through what they are going through. This perhaps indicates that members find both sources – experts and peers – trustworthy in different ways. This forum, I think, demonstrates the possibility for these two types of "expertise" – professional and experiential – to coexist, though scholarly and popular accounts at times place these types of knowledge at odds, with physician expertise and "approved" medical content considered inherently more credible.

At the same time, this analysis suggests that the potential for danger does exist in peer-based forums. A unique danger in a medical forum devoted to a complicated disease like Parkinson's is that patients may be especially vulnerable to trust and act on biased or incomplete information. Another unique danger is that the disclosure of intimate, emotional details may be treated insensitively. However, other members may recognize this vulnerability and aim to provide balanced advice or "drive out" members of the forum who are not there with the shared identity and purpose of helping

Parkinson's patients, even if it means diverging from the tone of politeness, civility and support that characterizes forum interaction. This behavior suggests a process of group members taking on a moderating role to help preserve trust in the community.

Another factor that is interesting, based on the specifics of this community, is how Parkinson's patients and caregivers interact. When Parkinson's patients interact with each other, explicit statements of identification (e.g., "We're in the same boat") often accompany advice. But in cases where caregivers post questions about their loved ones, respondents who are Parkinson's patients shift into a more educational than empathetic role, still basing their response on experiential knowledge and using a polite, supportive tone, but offering perspectives that help the poster understand their loved one's experience.

In summary, trust is signaled or built in the community through many factors: shows of politeness and support, identifying points of similarity in terms of physical and emotional experiences, and disclosure of personal and emotional information. Shared identity and purpose is a major aspect of trust, and this can be reflected in the ways that posters orient themselves to the group and to the disease. Trust appears to be built through repeated acts of disclosure, relationship-building, and social affirmation over time. In addition, medical expertise and experiential knowledge are both valued and complementary sources of authority for knowledge in the community, for different reasons. While trust is influenced in part by displays of medical expertise, in ways similar to the e-health webpages I analyzed, trust is also self-regulating, operating in ways that have much to do with how the community functions overall, most importantly in that the community consists of people on the same "journey."

Chapter 7: Conclusion

Summary of Findings

In this dissertation, I introduced the issue of trust in e-health, a product of the internet opening access to information at a broad scale. Medicine, as a discipline whose authority has traditionally been based upon expertise and hierarchy between physician and patient, is one domain in which this increased access has led to special concern in popular and scholarly circles. This dissertation intervenes in these ongoing discussions by asking "How does trust operate in e-health sites?" and does so from a rhetorical perspective. Through a comparative rhetorical analysis of three e-health sites (NIH.gov, WebMD, and PatientsLikeMe), I found that trust operates in e-health sites in ways one might expect but also socially in newer ways that are based upon community and experiential knowledge, aligning with the broad shift to Web 2.0.

Trust is established in e-health websites via well-recognized rhetorical means such as features that contribute to a credible, trustworthy ethos and that signal the quality and credibility of the information within the sites. Some rhetorical strategies were common across my sample. For instance, appeals to scientific or professional authority were used to bolster the credibility of even user-generated knowledge, pointing to the enduring persuasive power of science. It may be that peer-based sites "piggyback" on traditional credibility strategies, creating a context of familiarity to build upon with their more radical ideals. At the same time, personal and social credibility features were not limited to the medical social media site. They were present even in the most information-based site, pointing to a growing recognition on the part of official institutions that today's patients expect to exchange experiences and information online.

However, moving along the continuum from informational to interactive websites, I found that trust-promoting strategies mapped to the type of website, displaying interesting variation. I identified common categories of credibility features that may promote trust in websites, while also analyzing how each type of feature was deployed in different ways across the sample.[43] These are just a few of the most salient categories of credibility features that demonstrated a continuum across the websites:

- Design. Webpage design can convey an organization's identity – as an information repository in the case of NIH.gov, a more personalized information repository in the case of WebMD, and an interactive information sharing site in the case of PLM.
- Use of visuals. Different types of visuals appeared in each website, contributing to a more traditional expert ethos or a more participatory ethos – scientific imagery and educational illustrations in NIH.gov, quasi-scientific imagery and humanistic images in WebMD, and interactive, crowdsourced data displays and video of patient perspectives in PLM.
- Use of citation. Citation strategies hint at the source of authority underlying information's credibility – full citations to clinical trials in NIH.gov, partial citations to scholarly sources as well as webpages in WebMD, and "citations" to individual users' data in PLM.

[43] Warnick (2007) has argued that we view web credibility in terms of field dependence (in Toulmin's terms) – the notion that users evaluate credibility according to the field or context in which a website is situated, and the values within that field. This view moves us beyond a modernist, author-centered view of credibility. As an example, she compares the different criteria a user might consider when assessing information from an entertainment site versus a medical site. My study pushes this idea further by illustrating how the values that underlie credibility vary even within the same field of medical information. This is evident in the ways in which Parkinson's information, though essentially the same in content, is presented differently across my sample of e-health sites.

- Writing style. Writing style was deployed in each site's medical information, indicating levels of distance from the audience that signal the credibility of information in different ways – a somewhat distanced yet educational style in NIH.gov, an educational yet personal style in WebMD, and a primarily personal and visual style in PLM.

Each site conveyed, it seems, a credible and successful ethos (and the popularity of the sites points to their rhetorical success), but the use of different strategies contributed to each site's unique ethos: an official, scientific ethos in the case of NIH.gov, a professional but user-centered ethos in the case of WebMD, and a communal, personal ethos in the case of PLM.

A focused rhetorical analysis of an online patient community (the WebMD Parkinson's Community) allowed me to go deeper into the new personal, social contributors to trust that emerged in the first two analyses. Appeals to the physician's credibility as an expert, as well as WebMD's overall professional ethos, played a role in establishing trust in the community, but I also found that the rhetorical dynamics that promote trust cannot all be accounted for with a traditional view of ethos as the projection of a speaker's character and credibility. Trust is also built interactively through exchanges and processes, and is ultimately connected to how the community functions. In online community, patients can process medical information in light of their own and others' real-life, rich experiences. The shared experience of having Parkinson's seemed to create a context of trust, open disclosure, support, and kindness that patients may not receive from non-interactive websites, doctors, or family members. My study demonstrates different ways that trust operates in e-health, with social trust as an especially novel and important form of trust for medical information.

This social trust is reflected in the credibility features and ethos of interactive e-health sites, especially PLM, both in the website name as well as the emphasis on joining others in a larger mission. This sense of altruism towards fellow patients may be a unique contributor to trust for e-health sites.

Overall, my findings point to the future of e-health as patient-based, with the patient experience at the center and trust formed in personal, social ways (in addition to more traditional ways). This model is a significant departure from the hundreds of years that medical knowledge has resided in the hands of expert physician and researchers, and has many theoretical, pedagogical, and practical implications for rhetoric, technical communication, and e-health.

Implications

Rhetoric and Technical Communication Theory

In the introduction and literature review I explained how ethos is the way that rhetoricians get at the question of trust, so I will start there in terms of what this study suggests for rhetorical theory. Rhetoricians have long studied ethos, and digital ethos has been a topic of special import in recent years. My study can help explain how ethos operates online in a variety of e-health sites, most interestingly in patient-participatory websites, a setting which has not yet received sustained attention in the field. A rhetorical perspective on such settings is especially important as patients become more involved in their healthcare. My study also suggests that understandings of visual rhetoric and visual ethos might be enhanced by cataloging the visual means of conveying credibility in online, interactive spaces.

While my study shows the usefulness of ethos as a rhetorical concept for understanding digital communication, my study also displays the value of trust as an

overarching framework. The proliferation of digital information poses big questions, and framing those questions in terms of trust helps us situate ethos and think about the larger factors that make e-health (or any kind of online communication) work. Methodologically, this might mean conducting rhetorical analyses as well as interviews, surveys, or usability tests in order to gain a multi-angled perspective on the question of how trust operates rhetorically online. As was the case with this dissertation, a rhetorical perspective on trust could also mean broadening out to more expansive, multi-disciplinary bodies of literature on trust and credibility to inform rhetorical analysis. This act of stepping back helped me better understand the role of design, writing style, and visual features on websites, as well as community dynamics in a forum, that work to establish trust in e-health information. For the field of rhetoric, this is a new way to consider questions about information credibility, ethos, and persuasion. As I emphasized earlier, the connections are complex, and this dissertation is not an effort to synthesize these ideas in definitive ways; rather, it is meant to start down a new theoretical path.

In terms of technical communication theory, this study adds to others that have called for an expanded account of what "counts" as technical writing (Durack, 1997). Technical communication as a field has often studied medical discourse that takes place within institutional bounds, but researchers have become increasingly interested in e-health as an object of study (Bellwoar, 201; Koerber & Still, 2008; Kopelson, 2009; Segal, 2009). Like these scholars, I consider e-health websites to be technical communication, but I also think that patients' everyday health writing online is a form of technical communication – after all, patients are communicating about complex,

technical topics for various audiences. How these e-patient citizen technical communicators negotiate trust will continue to be a generative line of inquiry.

This dissertation brings the sub-fields of medical writing and medical rhetoric together with digital rhetoric. This combination is important because medical writing and rhetoric is especially illuminated when considered in light of patients' digital practices. People who study medical communication will need to account for the ways that doctors, patients, and everyday internet users are engaging with health information in new ways in the information age.

Technical Communication and Writing Instruction

My dissertation has highlighted the role of the web and social media in patients' information research and sharing. Students, too, are digital writers, and teaching methods must account for their research and writing processes and the skills they need as future professionals. The topics addressed in my dissertation yield numerous ideas for teaching approaches and assignments.

Technical communication and digital writing

Social media represents one way in which students are engaging in digital writing practices. Social media has also been growing into the workplace, meaning that technical communication instruction must be designed to prepare students for these changing digital environments (Blythe, Lauer, & Curran, 2014; Bowdon, 2014; Pigg, 2014). In-depth rhetorical study of these technologies is especially important in order to teach students not just how to use these technologies, but how to be responsible and reflective users of them.

Along with social media comes a more complicated notion of audience for technical communication. Audience analysis has always been central to effective

technical communication. Social media, though, blurs the lines of rhetor and audience. As my study supports, everyday technical communicators are contributing to and composing texts that are technical, digital, and multimodal. This may mean that professional technical communicators should be prepared for job descriptions that account for this change in audience. In some cases, their tasks might involve curating, managing, and synthesizing lay technical communication; in other cases, their tasks might involve producing or moderating social media communication for an organization.

Teaching rhetoric and online trust

Adding the dimension of trust to technical and professional writing courses opens a new way for students to evaluate their personal and professional digital communication. The following assignments could be part of a course about rhetoric, trust, and the internet, which could serve as a draw for majors other than writing.

Personal ethos analysis. A valuable assignment would be for students to conduct an ethos analysis, possibly of their own online presence (also an enlightening activity in terms of privacy). Most students are accustomed to doing "vanity searches" by now, but there are adaptations of this activity that could better situate it in rhetoric. One class activity I have co-led with a colleague involved asking students to look up information on the colleague (before meeting him) and form a sense of his ethos based only on his online presence. Then, the colleague entered the classroom, introduced himself, and talked through the ways he had tried to intentionally shape an ethos through his contributions and activity online (some of which was, of course, out of his control). This activity was interesting for students in that it helped them see the value in an intentional approach to one's online identity, as well as the potential for a mismatch between one's rhetorical intentions and the ultimate impression it may have on viewers.

To take this activity further, an instructor might have students evaluate an ethos in terms of trust ("Would you trust this person? Why or why not?") and articulate specific contexts in which an audience would need to make a choice to trust (hiring someone, adding someone to your social network, making a donation, etc.).

For a professional writing course, this activity could be accompanied by a plan for students to shape their online ethos in order to better gain the trust of audiences, in light of their personal and professional goals. One way to do this would be to create a personal website or portfolio. Students would carefully consider visual choices but also draft multiple context-specific versions of a professional biography to post online, including a "micro bio" for a social media site like Twitter. Another adaptation of the ethos analysis assignment, especially appropriate for a technical or business communication course, would be to do this activity as a service for a small business, complete with practical recommendations.

Review set. Another assignment to help students think about trust, credibility, and citizen technical communication would focus on user reviews and review sites. Students could look at reviews for movies, restaurants, apps, or electronics and consider what makes them effective or ineffective, then draft and post their own. Part of this project might involve comparing the credibility features of professional reviews to consumer reviews and discussing the implications of these differences. For instance, I have had students read *New York Times* movie reviews and write a review in that style, and then write a review to post on IMDB.com or Amazon.com. Students could also consider how they might adapt their message for a context like Twitter, and how to convey ethos despite a constraint on word count and a new environment.

Wikipedia revision. Wikipedia is a site that crystallizes much of the concern over crowdsourcing, anonymity, and misinformation online. Students could explore popular press articles and scholarly research on Wikipedia and its accuracy (e.g., Priedhorsky et al., 2007), then critique a Wikipedia article themselves. Consulting the revision history and citations would help students better understand the collaborative nature of much online writing. Taking the assignment a step further, students could edit the article and write a reflection on that process. Based on their collective experience, students might make recommendations on a "Wikipedia policy" for the use of Wikipedia in a writing class. This idea leads to another way in which my dissertation touches writing pedagogy.

Rethinking the "checklist" approach to source credibility

In addition to social media writing, another way in which students act as digital writers is that they are gathering sources from an ever widening base of online options and using different tools (social media, user-generated content) to aid them. For a long time, writing instructors have taught source credibility according to a fairly standard checklist of criteria. We want students to ask these questions of sources: Who is the author? What are their credentials? Is the information accurate? These criteria are certainly important, but they may be limited or inapplicable in some cases. The nature of online information makes credibility assessment simultaneously more important and more complicated. In line with other scholars (Lankes, 2008; Metzger, Flanagin, & Medders, 2010), I think instructors might adjust their instructional approaches in light of a more realistic perspective on how students actually use the web. My research can help bring nuance to discussions of source credibility in class.

In a class environment, there are a few practical ways instructors can rethink teaching source credibility, whether in a first-year writing class, technical and professional writing class, or medical writing class. First, a good way to orient students to the importance of credibility assessment is to have them compare websites. I have asked students to evaluate MayoClinic.org and RYTHospital.com. The latter is persuasively designed to look legitimate (see Figure 25), but it is a known hoax (supposedly an art student project). Despite its outrageous claims of designer babies and male pregnancy, students thought it was a credible website.

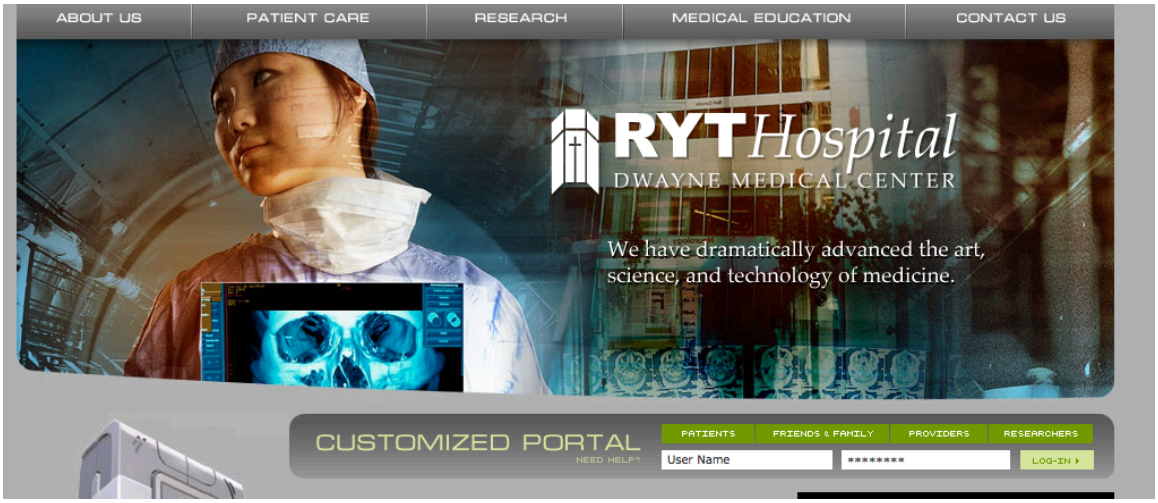


Figure 25: RYT Hospital, a hoax medical website

It would be valuable to point out to students how the site strategically replicates some elements of a credible site – a fake physical address, a photo of the president, a contact form, and references to medical doctors – for the purpose of deception. This activity can serve as a good wake-up call for students not to base credibility judgments on a first visual impression. Instructors might talk about how those quick judgments can still be used to help us navigate other sources, but that it is important to make

transparent the factors that go into our assessment of sources, not just the factors that are “supposed” to be valued.

One way to get students to think more closely about these complex processes of credibility assessment is to have them construct an extended annotated bibliography. Standard annotated bibliographies involve source summaries and, at times, explanations of the relevance of the source to a given research project. It would be fruitful to extend this activity to have students comment on the credibility of each source, and not just in terms of the standard criteria. They could comment on broader factors such as the influence of the search process or factors external to the information (Was it the first hit on Google? Was it cited in a Wikipedia article? Was it tweeted a lot? Had they heard of the organization authoring the information and already knew it to be credible?). It would be important to emphasize for students that entirely objective sources are not the goal because they do not exist. The assignment could open up discussions about when scholarly sources are necessary, and when non-scholarly sources might actually be more useful.

Rather than issuing a blanket requirement that students use only scholarly sources, instructors can be open to the ways that students might find social media and user-generated content to be useful for a writing assignment. Wikipedia, while still dismissed outright by some instructors, is becoming more accepted, at least as a jumping off point to more scholarly sources. Blogs, online comments, and discussion forums might provide students with a sense of public opinion on a current event that they might not get from established news publications. Following Twitter feeds for scholarly journals and thought leaders in a field could help students stay apprised of the most cutting-edge research on a topic. Asking students to think carefully about their

purpose and how sources can work together overall, I think, would better prepare students to navigate online information thoughtfully.

Teaching medical writing

Health and medical communication is a growing sub-field in technical communication. I imagine that courses devoted to medical writing will grow because the medical field increasingly needs both health professionals who can write, as well as technical writers who may have not been trained in medicine. While general technical communication principles like audience analysis and document design apply to medical writing, medical writing poses particular challenges. For instance, according to Dautermann, it can take place "in a context where split-second decisions may mean the life or death of acutely ill patients" (as cited in Heifferon, 2005, p. xv). My study suggests that medical writing instruction should also address how to communicate in digital forms. For medical writing students, rhetorically analyzing different types of medical information pages could reveal the complexities of writing style, technical definitions, visuals, interactivity, and source use and these features' connection to audience, purpose, and context.

Another idea for a medical writing class would be aimed at getting future medical professionals to discuss situations they might encounter with e-patients. It would be interesting to engage students in a case study where they discuss how they would respond to a patient who shows up to their office with results from their Google search, or other similar scenario. The goal would not be to come up with a right answer but to generate some good principles about how to deal ethically and compassionately with patients, not based on a stereotype of the cyberchondriac or of the inherent poor

quality of online medical information, but based on real knowledge of the complexity and wide variation of e-health and patients' online practices.

Web Design

My foray into rhetoric and trust in online environments points to some practical implications for web designers, web writers, and other professional technical communicators tasked with fostering community and a trustworthy web presence. My findings most immediately apply, of course, to e-health, but I begin by addressing what my study might mean for online writing instruction.

Design of online instruction

I have already shared ways instructors can help their students think about trust to inform their writing projects, but another consideration is the importance of trust to a successful classroom environment. While instructors can take steps to promote trust among students, in an online course, the role of *technology* must also be considered.

Online courses are becoming more popular, and, especially in writing courses where much of the learning takes place through small group interaction and peer feedback among students who have never met each other, instructors have been interested in how to foster a sense of community in the absence of a face-to-face classroom environment. As my study confirmed, dynamics like validation of others, politeness, ability to develop a reputation over time, and even humor all contribute to a functioning online community where trust can thrive, and such findings might even help teachers see interaction that they deem as off-topic as actually setting a foundation of trust that enhances interaction about class-related topics. Assuming that mutual trust among students and instructor is part of what makes a class community successful, instructors and administrators should attend to these dynamics. Practically, this

attention might involve instructors asking how their intervention in students' interactive spaces might promote or diminish trust, given teachers' role as authority figures. Again, many teachers and scholars are already thinking hard about the challenge of community and the instructor's role in online courses. However, bringing the lens of trust and associated literature from internet studies and other fields could provide additional insights and translate into a direction for classroom research.

At a different level, part of the answer to promoting trust in a class community lies in the design of course management systems and other digital spaces where students interact. Companies that develop such systems might take cues from social media sites that successfully deploy reputation systems and track metrics like helpfulness ratings from peers. Some software developed by writing scholars, for instance, collects data on the peer review process and enables students to rate helpfulness of feedback. Tools like this suggest the possibilities for capturing some of the social contributors to trust in computerized ways.

Design of e-health websites

My study has the most direct implications for e-health designers and communicators (though the implications could extend to any type of website where trust is crucial). One of the major findings of my study was how e-health sites of all types seem to be growing towards the social, if only in constrained ways (e.g., NIH.gov including a social media block). Patient-participatory sites like PLM enable sharing and information exchange in even more complex ways that patients seem to value.

Design of e-health webpages. As I mentioned in the introduction, e-health is a sensitive situation in terms of trust because people use online information to make medical decisions. Legitimate health organizations need to know how to make their

websites, and their information, stand out amidst the false, misguided, or incomplete medical information out there. If a governmental website needs to get the word out about, say, vaccines, knowledge of the features that promote trust is essential. Of course, many patients deliberately seek out official, expert, information-based sites already, because these patients trust that kind of information. Therefore, I do not mean to suggest that informational sites will or should go away. However, the finding that patient experience and similarity can be particularly persuasive to users might be leveraged in lieu of or in addition to more traditional credibility strategies that reflect hierarchical views of medical information (wherein experts educate lay people in unidirectional manner). According to Miller (2003), conflating ethos and expertise edges out goodwill and virtue,[44] the more relational aspects of ethos, and limits trust: "The impersonality of an ethos of expertise runs the risk of being persuasive to no one" (p. 202).

The issue of vaccination illustrates this need for a broadened view of how trust operates in e-health. Grant et al. (2015) compared the rhetorical strategies of official, pro-vaccine websites and vaccine-skeptical websites. The researchers found that pro-vaccine sites demonstrated a unidirectional, non-interactive model that played up the expertise of their sources, while vaccine-skeptical sites employed a wider variety of features and sources with a particular focus on creating communities. Studies that assess e-health websites on the basis of only their quality and accuracy do not tell us

[44] Miller also says of the technical, expert ethos: "the third component of *ethos*, *phronesis,* or "good sense" [at times translated "practical intelligence"], is transformed into a narrower and more technical form of knowledge, diminishing the practical, or relational, dimensions of knowledge itself" (p. 204). It might be valuable to explore potential parallels between Aristotle's phronesis (this more practical form of expertise) and a more expansive view of medical expertise as incorporating patient experience.

much about *why* patients trust the information, good or bad; rhetorical perspectives such as Grant et al.'s and my own can help to do that. Physicians and officials concerned with misinformation online have been interested in driving users away from potentially harmful websites. Instead, to promote good quality information, web designers for e-health might take cues from what actually seems to work in terms of trust.

E-health designers might promote trust by thinking of ways to represent the patient voice. The case of Medpedia reflects, perhaps, the importance of creating a space for patient interaction even in information-based sites. Medpedia, a medical wiki, was started in 2007 and was meant to be an authoritative online source for medical information. It restricted editing privileges to medical experts in an effort to create an alternative to low-quality medical articles on sites like Wikipedia. The website did not succeed; while there could be many reasons for this, some people have speculated that it failed in part because it shut out the patient voice[45] ("Medpedia, the medical Wikipedia, is dead," 2013).

Design of online health communities. As for interactive e-health spaces like patient communities, it would be valuable to consider how recommender systems and reputation systems can facilitate trust-building. The WebMD Communities made relatively little use of these tools, offering only modest options for filling out a profile and a limited use of helpfulness ratings. Patient social networks like PLM are finding sophisticated ways to summarize the things that matter in trust-building. As described

[45] The story of Medpedia aligns in some ways with the story of Nupedia, Wikipedia's predecessor. Nupedia was a general-topic web-based encyclopedia that was characterized by expert submissions and a "filter-then-publish" model of review ("Nupedia," 2015). Obviously, it did not catch on in relation to Wikipedia, a more open-access "publish-then-filter" model.

in Chapter 5, the “nugget” (see Figure 26 for a close-up) is a condition-specific visual summary of a patient’s health status. It indicates the patient’s history with the disease and how many stars they have earned for the thoroughness and currency of their profile data. It provides participation metrics in the form of how many comments a patient has contributed, and social validation metrics in the form of how many helpfulness marks a patient has received from others. Tools like these nuggets could prove to be interesting objects of study for scholars of online trust, health communities, technical communication, and visual rhetoric, particularly in terms of how users interpret and use these tools to make trust decisions online.

Figure 26: Example PLM nugget (identifying information obscured)

Ethical dimensions of tools like the patient nugget might also be explored, e.g., what happens when hugs and thumbs up beget more hugs and thumbs up, independent of the actual quality of the post? This concern also points to, at a broader level, the importance of making transparent the algorithms that underlie recommender systems. In Chapter 5 I brought up the underexplored notion of “algorithmic authority” which refers to a sense of trust in data and processes that do not necessarily have a human at the center. It would be helpful to view such systems as a tool rather than the

answer to the problem of online trust; how they interact with more traditional linguistic and rhetorical means for establishing trust would be interesting to investigate.

My research also reveals the difficult task that moderating online health communities can be. Expert or not, moderators must juggle the goals of ensuring quality information flow and showing respect for patient opinions and experiences. Often, these two goals are not at odds, but in cases where they are, moderators must think carefully about how to preserve trust in the community. In the WebMD Parkinson's forum, the physician moderator answered many user medical questions with knowledge but also empathy and prudence. In turn, patients came to view him as a valued resource. I imagine that expert, fact-based answers delivered in an impersonal manner would not have received as favorable of reactions. Designers of online health communities must think about the role of the moderator in terms of what patients need. Moderators might be present to answer questions or to oversee interaction in a more hands-off way. E-health sites that opt not to employ medical professionals as moderators might even consider how technical communicators could be specially qualified for the task of managing forum interaction and the flow of complex information (Frith, 2014).

Design of patient portals. While my study focused on e-health information sites available to all internet users, the implications of my study could also apply to medical institutions' patient portals, where patients go to communicate with their provider and access their test results and doctor visit summaries. This environment, where patients' medical data is stored, heightens the need for security. Thus, trust could be a helpful frame for considering design for such sites. It would be valuable for site designers and medical institutions to consider not just how to make the experience more usable for

patients (Mchome, Sachdeva, & Bhalla, 2010), but also more trustworthy. As my study suggests, institutions should be aware of patients' expectation of greater involvement in their care, as well as the great likelihood that they use the internet for health purposes. These patient behaviors and expectations could translate into more interactive and dialogic site designs for patient portals.

E-health and Medicine

The implications addressed above have touched on some enduring questions at the heart of e-health and the true ramifications of "the empowered e-patient." As discussed in the literature review, e-health has aligned itself with participatory medicine or the patient-centered healthcare movement, which takes patient agency as a central value. I talked about gatekeeping efforts by government officials and medical professionals and how some scholars think such efforts are not a realistic response to the problem of trust in e-health. I have come to agree with that perspective, if only because e-health is so pervasive that I cannot imagine it will soon be turned back. As one patient commented in an article by Arnst (2008), "This [participatory e-health] is happening, and the world has to deal with it" (p. 2).

My work illustrates the changing nature of credibility and the important role that community plays in decisions to trust online information, especially in participatory, peer-based spaces. Rather than dismissing these websites outright as unreliable, medical professionals should reflect on what users are getting out of this kind of information exchange. Many doctors are already seeing the value in patient social networks and recommending them to patients, and patients' self-tracking data can inform a doctor's diagnosis or treatment decisions.

I do not mean to suggest that peer-based spaces are free of dangers. From studying a year's worth of interaction in WebMD, I identified moments where a user shared a faulty website,[46] a troll invaded the forum to insult vulnerable members, a scam operation came online to defend itself using pseudo-scientific jargon, and a user was eager invest in a supplement in lieu of medical attention. Seeing these events listed in one place can be alarming, but another thing my study showed is that communities like the WebMD Parkinson's Community can be fiercely protective and work against precisely the kind of isolation and vulnerability that predators prey on.

Concerned media and scholarly accounts of e-health misinformation often rhetorically construct e-patients as isolated cyberchondriacs, vulnerable to quackery and claims of quick cures (Kopelson, 2009). For many patients, however, engaging with others in a support group is an essential part of making a disease more bearable, and the community can serve as an important tool in helping patients navigate other e-health information. Sillence (2010), in her analysis of an online health support group, concluded that "this community takes its role [in advice-giving] very seriously" (p. 392). Online communities can set standards for incoming users and claims, and they can even "train" other community members in critical thinking, awareness of risks, and the importance of considering multiple perspectives. Internet scholars have often lamented how the internet can serve as an "echo chamber" or "filter bubble" of likeminded thinkers, blocking out alternative viewpoints. I do not dispute this possibility, and I acknowledge that such an effect could be particularly damaging in an e-health context.

[46] Though this moment did not ultimately find its way into my analysis, I did observe a case in which a site I know to be a self-interested sham was recommended as a helpful resource about Parkinson's disease. The creator of the site had been banned from Wikipedia as a "sockpuppet" for making edits to the Parkinson's page (among others) in the form of links to his site.

However, disagreement, debate, and questioning can be vital and respected aspects of online communities, where patients may be of like illness but not always of like mind. Future research could examine the processes of collaborative credibility assessment in online patient communities.

Further complicating questions of information quality in e-health is the more recent trend of crowdsourced medical data and quantified self-tracking. As addressed in Chapter 1, ethical issues range from the validity of crowdsourced data to the potential for patient exploitation by companies. First, might patients be taken in by the "'bandwagon heuristic' whereby people assume that if many others think something is correct, then it must be correct — and thus credible"? (Metzger & Flanagin, 2013, p. 215). Rhetoricians have long critiqued positivist beliefs about the objectivity of science; when these new information forms and information-sharing websites adopt the aura of objectivity that comes from science, what are the ethical implications? Despite the presence of disclaimers about accuracy, how do people actually interpret the validity of the information? Indeed, the activity of sharing health data openly, the promises of big data, and the implications of crowdsourced data visualization in the realm of health are newly being explored. Signs point to this activity growing, especially as wearable technologies make the process more automatic and online tools make visualizations more sophisticated and usable. The time is ripe for scholars in the rhetoric of health and medicine to explore what patients might gain or lose by contributing to and relying upon such datasets.

Second, what are the ethical implications, from a privacy perspective, of companies collecting patient data at a large scale, and using it in perhaps undisclosed ways? Health information sharing sites are especially complicated to critique because

rhetoricians are often interested in agency and power relationships. In much medical discourse, the power dynamics are relatively obvious (according to a traditional doctor-patient relationship, for instance). Health information sharing sites provide control and a feeling of empowerment for patients that they may not get from their relatively disempowered positioning within the medical system. However, health information sharing sites introduce new power relationships, making it hard to gauge the extent to which patients are truly in control.

When I tell people about my research and the business model of some patient-participatory sites, this potential for exploitation is often raised as a prime concern. My study does not enable me to answer the question of whether such health data collection practices are ethical. Nor can I comment on whether the companies engaging in these practices are motivated by a desire to help patients or to make money; I do not possess a mythical etho-meter with which to objectively measure one's character. And indeed, if such a thing existed, the issue of trust would not be worth studying. Due to the unique ethical complications surrounding health information sharing sites, such sites should be a focus for rhetoricians.

Central to the question of why patients use e-health is the notion of medical expertise. At a broader level, many scholars have commented on shifting views of authority in realms beyond medicine (Hartelius, 2008; Lankes, 2008; Mackiewicz, 2009). In participatory medicine this shift in authority is reflected in the notion of patients as experts in their own right, a construction which is not without its complications. As Segal (2009) says, "the problem is not just that laypeople do not know what doctors know; it is that they *cannot* know it" (p. 353). It is an open question of what the construction of "expert patient" means and what the implications are. At any rate,

framing the issue of e-health in binary terms, as expert vs. patient, as dangerous vs. empowering, or as credible vs. not credible, is probably not productive. In my study, I found both medical expertise and experiential knowledge operating in e-health sites. It would be valuable to acknowledge how both types of knowledge might meet patients' needs in a complementary fashion. For instance, a professional drug information sheet can only tell a patient so much about potential side effects of a drug. The act of reading patient reviews and seeing aggregated quantitative rankings of side effects provides an entirely different kind of information about a drug that patients can factor into their decision-making and their conversations with their doctors.

A rhetorical perspective acknowledges the complexity within these conversations. It recognizes that technology, particularly new technologies, are a double-edged sword. Instead of viewing health information as a problem to be solved, or as the panacea that solves all patients' problems, I suggest we not use totalizing terms and, rather, take an in-depth look at what is actually happening in these new spaces. What we will find will help us understand both the risks and rewards of patients' engagement online. This recommendation leads me to address some additional future research directions suggested by my study.

Future Research

As suggested by my study, the foremost area in which to conduct future research is patient-participatory sites. My dissertation has pointed to the novelty of these sites in terms of the ways they construct ethos, drawing on different values and sources of authority than traditional medical discourse. Future research might specifically examine sites that bill themselves as medical information sharing sites or medical crowdsourcing sites to better understand, rhetorically, this new and uniquely

contentious aspect of e-health. A deeper study of how companies persuade users to contribute data would be enlightening, and would offer a contribution to studies of online privacy.

Along with study of data-sharing sites come additional ethical, legal, and methodological questions for researchers. Even sites that vaunt the value of open data may have limits on how it applies to external researchers. For researchers who wish to look deeper into these sites, how do we navigate questions of acceptable data use, both with these companies and with IRBs?

The growth of citizen science (or citizen medicine) initiatives, and professional or governmental boundary-keeping reactions, will also prove generative for rhetorical study. It would be interesting, for instance, to study documentation and rhetoric surrounding the FDA ban of the genetic testing company 23andMe.

While deeper rhetorical analysis into one patient website or across different websites would be valuable, a multi-method approach would also be well suited to studies of trust and rhetoric. DePew (2007) argues that “we should try to avoid the separation of discourse from rhetorical situation, from rhetor and audience” (p. 66). So, while a textual analysis is useful, a researcher would need to consult with participants to get at broader dimensions of user behavior such as motive and effect. My analysis did not involve participants, but DePew’s argument helps me imagine some future research directions where I could involve users. In particular, interviews or surveys, or even observing a single user as they approach search engines, select sources, and make decisions based upon them, would be a very interesting complement to a rhetorical analysis of the sources.

Possibilities exist for further study of trust in online communities, in order to more deeply explore how trust seems to be influenced by dynamics such as privacy, anonymity, types of gatekeeping (e.g., moderators), or even medical condition.

Besides studying health information in online, participatory contexts, technical communication scholars should attend to patient-participatory genres situated within medical institutions. Indeed, this dissertation is written at a time of great change not just in the e-health landscape but in medicine in general. Initiatives like OpenNotes, mentioned in Chapter 2, are catching on and requiring a rethinking of the audience for official medical documentation; the next step may very well be inviting patients to contribute to their own medical notes. According to one reporter, "the open records movement is moving beyond transparent, to interactive. That is, what if you could not just see your doctor's medical notes but actually comment on them and contribute to them?" (Goldberg, 2015, para. 4). Writing scholars are well equipped to investigate these interesting changes. On the flip side, a focus on the benefits of e-health and participatory medicine also raises the question of how it changes the medical experience for "non" e-patients. In this age of self-sufficient medicine, what happens to the patients who cannot or will not take on the burden of educating themselves?

I have posed multiple directions that researchers could fruitfully explore regarding trust and e-health. In fact, I believe these issues *need* to be explored given the significant role that patients are playing in shaping e-health. Lay people are accessing, interpreting, exchanging, and communicating about complex technical and medical topics in brand new ways. These changes leave important questions wide open for researchers in rhetoric and technical communication.

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